

**Patients', Family Caregivers', and Nurses' Stories
of Acute Exacerbation Events of
Chronic Obstructive Pulmonary Disease**

Patricia Hill Bailey

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DECLARATION

I declare that the following thesis has been composed by myself, and that the work is my own.

DEDICATED TO

**Bruce
Joel
Arynn**

IN MEMORY OF

My Mom

ACKNOWLEDGEMENTS

I wish to acknowledge the many people whose contributions and support have made the completion of this thesis possible.

First of all, I must thank the patients, family caregivers, and nurses who entrusted me with the stories of their experiences of acute exacerbation events. These individuals believed that their contribution to this work would enhance the care of individuals suffering from chronic lung disease and frightening breathlessness episodes.

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ABSTRACT

Chronic Obstructive Pulmonary Disease (COPD) is a progressive degenerative respiratory disorder which affects approximately 25% of adult males and 22% of adult females in Canada. As COPD progresses many individuals experience frequent acute exacerbations of incapacitating dyspnea (breathlessness) requiring emergency admission to hospital. These episodes contribute to a major illness burden for both the health care system and families who are living with this chronic illness.

Extensive research has been done on the pathophysiology of COPD and the physiological aspects of dyspnea. To date, however, the precise physical mechanism of breathlessness is still unclear. Lack of strategies to effectively reduce the distress of uncomfortable breathing in individuals experiencing an acute exacerbation of COPD continues to present important challenges to health care providers. Review of COPD and chronic illness literature suggests that families are central to the effective adjustment of chronically ill individuals to the lifestyle changes necessitated by COPD. In particular it is suggested that families are intricately involved in the management of acute exacerbations of COPD. However, no research has been done which supports this belief.

The purpose of this study was to develop a description of the acute exacerbation event of COPD: a theoretical understanding of this event that may assist nurses in their work with COPD patients and their family caregivers. A qualitative research design was used in order to uncover meanings of an acute episode of chronic lung disease for the patient, their family caregivers, and nurses. The main method was in-depth

interviews conducted during the patients' hospitalisation necessitated by an acute exacerbation event. The interview protocol was based on Strauss et al.s' (1984) theoretical model of managing a "medical crisis" of a chronic illness.

A number of genres of stories were identified in the interviews of the ten participating patient-family-nurse units. These stories, within the context of the interviews, were analysed systematically using a combination of two narrative analysis strategies: Labov and Waletzky's (1972) functional model and Agar and Hobbs' (1982, 1983) coherence model. Analysis was informed by attention to discursive and rhetorical aspects of the stories.

The stories shed light on the patients', family caregivers', and nurses' understandings of the meaning of living with COPD characterised by acute exacerbation events. Patients and family caregivers told stories about their experience of the fear of death, their perceptions of the patients' physical and emotional vulnerability, and their understanding of the causes of chronic and acute illness. Nurses told stories that described their care of patients on the in-hospital unit. In general the patients' and family caregivers' stories portrayed acute exacerbation events as liminal experiences; and highlighted patients' perceptions of themselves as vulnerable. The nurses' stories described the COPD patients as anxious individuals.

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CHAPTER 1

INTRODUCTION

My interest in the needs of family members of hospitalised individuals began in the early 1980's. From 1980 until 1987, I worked as a staff nurse in a twelve bed medical-surgical intensive care unit (ICU) and cared for patients and families during the overwhelming crisis of acute illness and death. This patient group included COPD patients and family caregivers during the crisis of acute exacerbation events. Colleagues frequently expressed concern that care of both the patient and the family during the crisis of intensive care was an arduous task for nurses to assume. Often we were uncomfortable in this dual role. While the physical care of the acutely ill patient was familiar territory, a clear understanding of the needs of family members was not available to us and hence the strategies adopted to assist these families were often ad hoc.

Family Needs Research

Therefore, as part of my master's work at McMaster University in the Masters of Health Sciences program, I began to look at the needs of families who had a family member hospitalised in an ICU (Bailey, 1986). Following my acceptance of a teaching position at Laurentian University School of Nursing, two colleagues and I established a research team to further investigate family needs. To date this research program has investigated family needs in a variety of settings. Data were gathered from individual

family members using a modified version of Molter & Leske's (1983) well known 46-item self-report Critical Care Family Needs Inventory (CCFNI) (Hickey, 1985). Questions were added to reflect the specific visiting policies and religious practices in the different regions in Canada where the data were collected (Rukholm, et al., 1991; Rukholm, et al., 1992; Rukholm, Bailey, & Coutu-Wakulczyk, 1991).

Congruent with previous research done using the CCFNI in the USA, our research found that the needs identified by family members of critically ill patients included the need for information and assurance of the best care for their relative (Hickey, 1985; Rukholm, et al., 1991). For some authors the logical next step in family needs research was the development of intervention studies to meet these consistently identified priority family needs (Dracup, 1987; Simpson, 1989). However, although limited, the work done with specific disease groups of ICU and non-ICU families has demonstrated that there may be important differences in the needs expressed by these specific family member groups. The reasons for these differences are as yet unclear; it is suggested that the differences may be related to both the acuity of the illness experience and/or the actual disease process being experienced by the family and the individual (Mathis, 1984). In addition, no research has looked at disease-specific family needs of this population from the individual's or family's perspective.

At present, my clinical practice with nursing students, as a faculty member, is primarily in caring for individuals/families during an acute phase of their chronic illness. Consequently, the focus of my family needs research is with these family groups. Since the early 1960's, there has been a growing awareness of the increasing numbers of individuals and families living with long-term illness (Curtin & Lubkin, 1995; Dimond & Jones, 1983; Dluhy, 1995; Gilliss et al., 1989b; Payne & Lubkin,

1995); Strauss et al., 1984; Leahey, & Wright, 1987). Indeed, more and more, hospital beds are occupied by individuals during an acute episode of their chronic illness (Strauss & Corbin, 1990; Strauss et al., 1984; Thorne, 1993). Among these are the large hospital populations of cancer, cardiac, orthopaedic and respiratory patients. There is now also a growing acknowledgement that families are the primary caregivers for individuals with long-term illness (Gilliss et al., 1989a; Leahey & Wright, 1987; Miller, 1992; Sexton & Munro, 1985), and recognition that changes in the structure of health care delivery increasingly requires these families to assume an even greater responsibility for caregiving (Gilliss et al., 1989b; Petty, 1985b; Thorne, 1993).

The Problem

Chronic Obstructive Pulmonary Disease (COPD) is one of these disabling and expensive chronic illnesses (Burns & Nicols, 1991; Petty, 1985a; Rabinowitz & Florian, 1992). It is characterised by frequent acute exacerbation requiring emergency hospitalisation (Anthonisen, et al., 1987; Burns & Nicols, 1991). An acute episode of COPD can occur as frequently as four times per year and take from three to four weeks to resolve. The acute exacerbations appear to be associated with respiratory infections which increase the respiratory work of an already compromised system (Anthonisen, et al., 1987; Petty, 1985b).

The COPD patients and family members I cared for in the intensive care unit were extremely anxious and afraid. However, limited research has been done to understand acute episodes of COPD requiring emergency hospitalisation or the needs of families who must manage these acute events (Miller, 1992; Strauss & Corbin, 1990; Wright & Leahey, 1987). Continued investigation of the needs of family members living with

chronic illness, including COPD, is therefore imperative in order to minimise use of expensive resources as well as provide maximum support for the family as primary care giver (Burns & Nicols, 1991; Nett & Petty, 1985).

Research Aim

The specific aim of this research therefore was to develop an understanding of the patients', family caregivers' and nurses' perceptions of the complex event of an acute exacerbation of chronic lung disease characterised by extreme dyspnea and requiring emergency hospitalisation. The underlying assumptions of the qualitative research approach "fit" with the research aim of describing the meaning of this complex event from the perspective of the patient, family caregiver, and nurse. The following chapters outline the process of this study.

Organisation of the Thesis

In Chapter 1 I introduce my experience with family units and their experiences of chronic illnesses, specifically acute exacerbation events of COPD requiring emergency hospitalisation. The discussion in Chapter 2 demonstrates that COPD is a major chronic illness characterised by acute exacerbation episodes; that dyspnea or breathlessness, the major presenting symptom during these acute episodes, is poorly understood and inadequately managed by health care professionals; that there is limited research done with families of individuals with COPD; and that the patients', family caregivers', and nurses' experiences of an acute exacerbation event have not been previously examined.

In Chapter 3 the two main conceptual threads identified throughout the literature

review, chronic illness and family research, are addressed. The discussion demonstrates that Strauss et al.'s (1984) chronic illness model presents a systematic way of understanding the very complex nature of the chronic illness experience. It also shows that families are central to the effective adjustment of chronically ill individuals to the challenges necessitated by COPD.

The qualitative paradigm in general is reviewed in Chapter 4. Narrative analysis as a form of ethnographic qualitative research is also examined. The discussion related to narrative inquiry includes a clarification of what is meant by a story in narrative analysis research, a brief description of three models of story analysis, an examination of the controversial issue of the assessment of the quality or goodness of interpretive research (and more specifically narrative analysis), a review of the utilisation of narrative analysis in nursing research, and a description of the analytic strategy used in this study.

The study setting, participants, and data collection process is described in Chapter 5. In Chapters 6, 7, 8, and 9 the patients', family caregivers', and nurses' accounts of their experiences of acute exacerbation events of COPD necessitating emergency hospitalisation are presented. The analysis illustrates how the meanings of an acute dyspneic event can be communicated through stories and outlines the differences between patients', family caregivers', and nurses' talk about their experiences of acute episodes. More specifically, Chapter 6 presents the patients' and family caregivers' stories of death. Chapter 7 includes stories of the patients' physical and emotional vulnerability. The patients' and family caregivers' understanding of the causes of chronic and acute illness are described in Chapter 8. Nurses' stories that outline the care of patients on the in-hospital unit are presented in Chapter 9.

In Chapter 10 conclusions are drawn from the meanings of the stories told by patients, family caregivers, and nurses; the potential implications of this new knowledge for nurses' care of patients and family caregivers are described; the utility of a narrative analysis approach in the examination of interview data is expanded; and the implications of this work for future research is addressed.

CHAPTER 2

LITERATURE REVIEW

What is it like to experience an acute exacerbation of chronic obstructive pulmonary disease? Individuals with COPD undergo frequent emergency hospital admissions (Burns & Nicols, 1991). These critically ill individuals present at health care institutions incapacitated by severe shortness of breath/dyspnea (Gift, Moore, & Soeken, 1992; Kinsman et al., 1983a; Kinsman et al., 1983b; Kroenke, Arrington, & Mangelsdorff, 1990; Mahler, et al., 1992) They are usually accompanied by family members and, as indicated above, are extremely anxious and afraid. The individuals are exhausted and their energy is completely focused on doing the work of breathing. To date, however, minimal research has been done to understand the frightening occurrence of an acute exacerbation event and the support needs of the expanding cohort of families, who, living with chronic illness, must manage frequent, intermittent hospitalisations (Miller, 1992; Strauss & Corbin, 1990; Wright & Leahey, 1987).

It is both the sick individual and the family living with COPD that need assistance in managing acute exacerbations of this disease (Gilliss et al., 1989b; Leahey & Wright, 1985; Thorne & Robinson, 1988). Indeed much of the assistance the COPD individual receives is the responsibility of both the family and the nurse. For the nurse, the provision of effective support requires an awareness of the chronic disease process with which the family lives and the management strategies commonly employed to cope with this circumstance. This understanding must also include an

awareness of the patient's and family caregiver's perceptions of acute exacerbation events.

The following literature review is intended to show that COPD is a major chronic disease characterised by acute exacerbations of intractable dyspnea requiring frequent hospitalisation. It includes an overview of the research on dyspnea, the symptom precipitating acute hospitalisation of individuals with COPD. This review of the dyspnea literature will show that this symptom is poorly understood and inadequately managed by health care providers. Finally, a critical analysis of the research done with families of COPD sufferers will illustrate the necessity for further investigation of the needs of family members living with this chronic illness.

Chronic Obstructive Pulmonary Disease

COPD is a progressive degenerative respiratory disorder which affects approximately 6.3% of adult males and 5.7% of adult females in Canada (Goldstein, 1998). Those stricken with COPD include 15% to 20% of smokers between 55 and 85 years of age (Coultas & Samet, 1989; Mahler, 1993). Current epidemiological data indicate that it is an increasing major health issue world wide (Mahler, 1993; Mak, 1997; Manfreda, Mao, & Liveten, 1989). In western countries for individuals between 55 and 74 years of age, it is the third leading cause of death among men and the fourth leading cause of death for women.

It is important for the reader and the researcher to have, as background information, an understanding of the full context of chronic obstructive pulmonary disease and its trajectory. COPD is a process identified by the presence of anatomical

changes in the lung parenchyma¹ characteristic of emphysema and/or the functional disturbances most commonly associated with chronic bronchitis (Mahler, 1996). This syndrome results in the development of non-reversible airways obstruction (Burrows et al., 1987; Snider, 1989). Asthma, uncomplicated by emphysema or bronchitis, in contrast, is a form of obstructive pulmonary disease in which there is usually complete reversibility of airways obstruction. With advances in medical treatment, asthmatics have a more predictable and benign clinical course, and hence this disease is often excluded from the definition of chronic obstructive pulmonary disease (Burrows et al., 1987; Snider, 1989). Therefore, in this literature review the definition of COPD generally included individuals suffering from the chronic illnesses of either emphysema or bronchitis.

Individuals with COPD experience a gradual onset of exertional dyspnea/breathlessness which they often mistakenly attribute to increasing age (Mahler, 1993, 1996). Permanent underlying pathological changes in the lung tissue resulting in a 50% reduction in respiratory reserve, however, are frequently present before symptoms become troublesome and individuals seek help (Nett & Petty, 1970; Petty, 1985b). The degenerative changes continue, and individuals with COPD have a shortened life expectancy of between 4 to 10 years following diagnosis (Anderson, 1995; Burrows et al., 1987; Higgins & Thom, 1993; Pearlman, 1987). As the disease progresses individuals experience increasing levels of dyspnea causing physical disability (Narsavage, 1996). Other symptoms accompany the incapacitating shortness of breath. They include fatigue, sleep difficulties, respiratory congestion, irritability,

¹ Parenchyma refers to "the essential or functional elements of an organ" (O'Toole, 1997, p. 1203).

anxiety, decathexis², hopelessness, memory loss, headaches, nausea, peripheral sensory complaints and loneliness (Gift & Pugh, 1993; Janson-Bjerklie et al., 1986; Kinsman et al., 1983a, 1983b). Physicians (Mahler, 1993; Nett & Petty, 1985) and nurses (Cossette & Léveques, 1993; Sexton & Munroe, 1985) recognise that families are the primary caregivers as COPD sufferers become unable to carry out their normal activities of daily living or attempt to manage acute exacerbations of their disease.

The degenerative pulmonary changes which affect both the lung tissue and the muscles of respiration, compromise the individual's ability to respond to any increased demand for ventilation (West, 1987). These degenerative pulmonary changes are accompanied by an increase in the frequency of acute respiratory decompensation episodes (Burrows, 1985; Tattersfield & McNicol, 1987). Acute exacerbations of incapacitating dyspnea requiring professional care occur with increasing frequency during the illness trajectory; individuals may experience as many as four acute exacerbations of COPD per year (Anthonisen et al. 1987; Petty, 1985b). In Canada, the average length of hospital stay in 1985-86 for adults between 65 and 74 years of age with a diagnosis of bronchitis, emphysema and/or allied conditions was 15 days. For individuals 75 years and older the average length of stay increased to 28 days. If the diagnosis was pneumonia, the average length of stay ranged between 21 and 37 days for individuals between 65 and 74 years of age and 75 years and older respectively (Statistics Canada, 1989). These hospitalisation days represent an important illness burden for both the health care system and individual families living with this chronic illness.

² Decathexis refers to a loss of interest in others, food, and things in general (Kinsman et al., 1983a).

Dyspnea the Principal Symptom of COPD

Individuals with COPD experience frequent emergency hospital readmissions (Burns & Nichols, 1991). These critically ill individuals present at health care institutions incapacitated by severe shortness of breath (Gift et al., 1992; Kinsman et al., 1983a, 1983b; Kroenke et al., 1990; Mahler et al., 1992). The literature dealing with dyspnea notes that uncomfortable breathing is associated with a number of pathological conditions such as congestive heart failure and asthma, and that treatment of the diseases associated with dyspnea frequently results in relief of the symptom. However, when the related pathology is non-reversible, as in COPD, limited options are available for management of acute dyspnea by either the individual or health care professional.

Research has been undertaken therefore to understand both the physiological and psychological mechanism of dyspnea in order to facilitate the search for therapeutic interventions for conditions with non-reversible underlying pathology (COPD). Researchers have attempted to define dyspnea and studies done from a medical perspective have focused on the physiological mechanisms and clinical measurement of this subjective sensation (Killian & Campbell, 1996). Nursing research done on COPD has focused primarily on the experience of breathlessness and the psychological factors associated with the perception of dyspnea experienced by individuals with respiratory disease.

The literature contains a number of medical and nursing reviews summarising the current knowledge of dyspnea (Altose, 1985; Burki, 1987; Campbell & Guz, 1981; Carrieri et al., 1984; Gift, 1990; Killian & Campbell, 1985; Lareau & Larson, 1987; Manning, Mahler, & Harver, 1993; Schwartzstein et al., 1990; Tobin, 1990) (see

Table 1, Appendix A). These reviews present a definition of dyspnea, a summary of the research findings regarding the genesis of dyspnea, its measurement, and current management strategies. The literature will be reviewed using these topics in order to indicate both the extent of the understanding presently documented and the gaps in knowledge which still exist.

Definition

Dyspnea is commonly defined by the above authors as some form of difficult breathing (Tobin, 1990). It has been described as "an unpleasant or uncomfortable awareness of breathing or the need to breathe" (Schwartzstein et al., 1990, p. 185), or "the unpleasant, subjective sensation of breathlessness" (Carrieri & Janson-Bjerklie, 1986, p. 436). They make clear that dyspnea must not be confused with observed changes in either rate or depth of respiration that may not produce a subjective experience of breathlessness (Gift, 1990, 1993). Indeed there is a growing recognition "... that dyspnea, like pain, is a term that subsumes many sensations" (Schwartzstein et al., 1990, p. 186). The limited number of formal studies investigating the language of breathlessness have suggested that the quality and hence descriptors used to describe the experience of difficult breathing differ according to individual circumstance or underlying respiratory disease pathology (Janson-Bjerklie et al., 1986; Killian, 1985; Schwartzstein & Cristiano, 1996; Simon et al., 1989; Simon et al., 1990). However, more research in this area is required in order to develop clinically useful categories.

Physiological Mechanisms of Dyspnea

Several writers also generally conclude that dyspnea is a complex phenomenon,

whose genesis from a physiological perspective is associated with a number of elements involving sensory perception, central processing and motor commands. The common theoretical physiological categories proposed in these presentations include factors associated with respiratory effort or work of breathing, chemoreceptors or chemical factors affecting respiratory drive and mechanoreceptors or sites of dyspnoeogenesis. These theoretical constructs have been extensively investigated.

In general, there is consensus in the literature concerning the physiological research that suggests that the degree of perceived breathlessness is proportional to respiratory effort. That is, the greater the unsuccessful respiratory effort exerted by an individual, the greater the sensation of breathlessness experienced (Campbell & Howell, 1963; El-Manshawi et al., 1986; Jones, 1992; Jones & Wilson, 1996; Killian, 1985; Killian et al., 1984; Killian & Gandevia, 1996). Although cognisant of its significant contribution to the understanding of the phenomena, investigation of this "mechanically inappropriate" position is not, however, supported as the complete explanation of reported breathlessness in all clinical situations (Adams, 1996; Adams et al., 1985; Demediuk et al., 1990).

Other factors related to biochemical and mechanical stimulation have also been offered as partial explanations of the phenomena. Research into the role of chemoreceptors as co-collaborators in the precipitation of dyspnea has also proven controversial and inconclusive (Burki, 1987; Tobin, 1990). This debate has centred

on the independent and combined effect of hypercapnia³, hypoxia⁴, and muscle contraction. Earlier work contended that elevations in arterial carbon dioxide did not contribute to sensations of dyspnea (Nobel et al., 1970). Current research asserts, however, that hypercapnia does contribute to the sensation of uncomfortable breathing both independently and in the presence of respiratory effort (Adams et al., 1985; Chonane et al., 1990; Freedman et al., 1987).

It is believed that the mechanoreceptors in the upper and lower airways, lung parenchyma, and chest wall likewise contribute to the genesis of uncomfortable breathing. A plethora of respiratory research has demonstrated that afferent⁵ information from these peripheral sensors does moderate ventilatory patterns and is essential to the perception of dyspnea (Breslin, 1992a, 1992b; Burgess & Whitelaw, 1984, 1988; Eldridge & Chen, 1996; Killian & Gandevia, 1996; Liss & Grant, 1988; McBride & Whitelaw, 1981; Rodenstein et al., 1985). Stimulation of the trigeminal nerve⁶ for example, can either reduce or promote the sensation of difficult breathing (Schwartzstein et al., 1987; Simon et al., 1991). Pursed-lip breathing⁷, hypothesised to alter the transmural pressure gradients and generate afferent sensory messages, also

³ Hypercapnia refers to an "excess of carbon dioxide in the blood, indicated by an elevated PaCO₂ as determined by blood gas analysis, and resulting in respiratory acidosis" (O'Toole, 1997, p. 772). Hypercapnia can be a life-threatening situation (Smeltzer, & Bare, 1996).

⁴ Hypoxia refers to decreased supply of oxygen to the body tissues and is manifested by changes in mental status such as impaired judgement, agitation, confusion, and lethargy. Hypoxia can be a life-threatening situation (O'Toole, 1997; Smeltzer & Bare, 1996).

⁵ Afferent information refers to information conducted from the lung parenchyma, muscles, and peripheral chemoreceptors to the central nervous system (O'Toole, 1997).

⁶ The trigeminal nerve is the fifth cranial nerve. It supplies motor and sensory fibres to the face including the nose and mucus membrane of the mouth (O'Toole, 1997).

⁷ Pursed-lip, (Breslin, 1992a, 1992b), pursed lips, (Sitzman, Kamiya, & Johnston, 1983), pursed lips (Tiep et al., 1986) breathing (PLB) refers to a breathing technique in which air is inhaled slowly through the nose and then exhaled slowly through pursed lips (O'Toole, 1997).

ameliorates the feeling of breathlessness (Breslin, 1992a; O'Donnell et al., 1987, 1988; Sitzman et al., 1983; Thoman et al., 1966). The research done with heart-lung transplant individuals who possess denervated lungs⁸ illustrates the as yet little understood contribution of vagal⁹ input in modifying the sensation of breathlessness (Sciurba et al., 1988). Finally, chest wall receptors also appear to affect the perception of dyspnea. In some research the greater the chest wall movement, the larger the perceived reduction in difficult breathing (Breslin, 1992a; Schwartzstein et al., 1987).

Whereas the evidence reviewed suggests a relationship between respiratory effort or work, chemoreceptors and mechanoreceptors, the precise physical mechanism of dyspnea is still unclear. In order to facilitate the development of effective strategies for relief of this distressing symptom in individuals with progressive disease, researchers continue to attempt to understand these mechanisms.

Psychological Aspects of Dyspnea

Although the affective contribution to a perception of breathlessness has never been denied, the nature of its contribution has been elusive (Guz, 1996). Limited research has been conducted to explain why individuals with apparently comparable lung disease report varying levels of respiratory distress (Traver, 1988). It is important to note that, as Adams and colleagues (1985, 1986) have demonstrated, there are differences in the perception of respiratory sensory stimuli among healthy adults which as yet remain unexplained. Some studies have therefore focused on the

⁸ Denervated lungs are lungs that have had the nerve conduction interrupted. Denervation occurs with individuals who have undergone a lung transplant (O'Toole, 1997).

⁹ Vagal refers to the vagus or tenth cranial nerve. This nerve serves the "...structures of the chest and abdomen as well the head and neck" (O'Toole, 1997, p. 1698).

psychological differences among people with COPD and/or between COPD sufferers and non-diseased individuals in order to explain disparity in the experience of breathlessness severity. Research has shown that individuals with COPD can also suffer from significant depression, yet the nature of the relationship between the experience of COPD and depression is unclear (Gift et al., 1993). Work by Burns and Howell (1969) in the early 1960's unequivocally demonstrated that individuals concurrently suffering from psychological illnesses including depression, anxiety or hysteria could present with breathlessness disproportionate to their underlying lung pathology as measured by pulmonary function testing. These researchers report that treatment of the underlying psychopathology in these subjects relieved the complaints of dyspnea.

In addition, it is important to note that subsequent research has shown that, although individuals with COPD as a group do report substantially higher levels of reactive depression than other medical patients, in the absence of psychiatric illness, there is no correlation or causal relationship between the perceived severity of dyspnea and the degree of depression (Light et al., 1985; McSweeney et al., 1982). McSweeney and colleagues (1982), investigated the quality of life of a large sample of individuals with severe COPD (n=203). These informants were individuals enrolled in a multicentered trial (the Nocturnal Oxygen Therapy Trial), and required oxygen therapy on a daily basis. The COPD study participants were compared with a control group of 73 disease-free individuals, matched for age, sex, race, education, and socioeconomic status with a randomly selected subgroup of the COPD informants, on three self-report measures concerned with quality of life. Data from the Minnesota Multiphasic Personality Inventory (MMPI), the Profile of Mood States (POMS), and

the Katz Adjustment Scale (KAS) demonstrated that 42% of the COPD subjects suffered from reactive depression.

Light et al., (1985) studied convenience sample of 45 men with moderate to severe COPD. Persons with a history of psychiatric illness were excluded from the study. The degree of depression was measured using the Beck Depression Inventory (BDI). Forty-two percent of the COPD sufferers in this study also had scores on the BDI which indicated significant reactive depression. It is important to note that neither of these studies reported data on the medication regimes of the subjects in their studies.

A more recent project by nurse-researchers has suggested that there may be a relationship between the administration of long-term low dose steroid therapy and an increase in the levels of depression experienced by COPD individuals (Gift et al., 1989). In this study 20 COPD sufferers receiving steroids were compared with 20 individuals with COPD not receiving steroids using the Beck Depression Inventory (BDI) and the Brief Symptom Inventory (BSI), self-reports of depression. The informant groups were matched for age, disease severity, blood gas values, and somatization scores. The writers showed a significant difference in the level of depression reported by the informants receiving steroid therapy. The researchers did not assess the participants for levels of depression prior to assignment to treatment groups and therefore recommend a prospective study in order to validate their findings.

Gift et al. (1986) have also explored the relationship between the severity of breathlessness and several psychological and physical factors generally associated with dyspnea in individuals suffering from severe COPD. In their initial work a convenient sample of 20 subjects hospitalised in a chronic care facility with a diagnosis of COPD

were studied to determine if depression and anxiety and airway obstruction, respiratory rate, sighing, paradoxical breathing¹⁰ and use of accessory muscles of respiration varied significantly within patients at different levels of breathlessness. An unspecified number of the participants were receiving continuous low flow oxygen by nasal prongs.

The physical and psychological variables were measured at low, medium and high levels of dyspnea as determined by a 20 mm (1 standard deviation) or greater difference on a vertical visual analogue dyspnea scale (VADS), validated by the authors as a first step in the study. Depression and anxiety were measured using the Brief Symptom Inventory (BSI), and an abbreviated form of the symptom checklist-90-revised (SCL-90-R), and the Spielberger State Anxiety Inventory (SAI). Sighing and the presence of paradoxical breathing were observed for during the course of each 30 minute clinical assessment by one researcher. During the same observational period each participant's respiratory rate was counted for one minute. The depth of respiration and use of accessory muscles of respiration (represented by a rise in the clavicle during inspiration) were visually noted on a three point scale by the same researcher (1, shallow or absent, 3, deep or severe). Peak expiratory flow rates (PEFR) were measured using the Wright Peak Flow Meter. The highest reading of three attempts was used.

As anticipated, the researchers reported a relationship between increased anxiety and use of accessory muscles as dyspnea increased. However, a relationship between depression and level of difficult breathing was not identified. Moreover, similar to the

¹⁰ Paradoxical breathing is "a type of breathing in which all or part of the chest wall moves in during inspiration and out during exhalation" (O'Toole, 1997, p. 1194).

work of others (Adams et al., 1985, 1986; Light et al., 1985; McSweeney et al., 1982), there was no change in the pulmonary function test values for different levels of breathlessness. Sighing and paradoxical breathing were also not observed by the researcher. Contrary to expectations, no relationship was found between respiratory rate and dyspnea and/or anxiety. The authors suggest that this is perhaps explained by the fact that the subjects were already at high respiratory rates for even low perceived levels of dyspnea and hence that respiratory rates may not therefore be as sensitive as predicted and/or that the administration of oxygen may have minimised an increase in respiratory rate during episodes of more severe breathlessness.

In subsequent work, Gift and Cahill (1990) again explored the relationship between psychological and physiological factors during episodes of more or less severe dyspnea with convenience sample of six COPD patients recruited from a veterans' medical centre in Baltimore, Maryland. The participants, three of whom were receiving oral prednisone¹¹, were assessed during low and high levels of dyspnea, using the same measurement tools as in their previous work (Gift et al., 1986). Additional physiological factors presumed to be related to dyspnea, depression and anxiety, were also measured. These included blood gas values for PaO₂¹² and PaCO₂¹³ and plasma cortisol levels¹⁴. The results of this study again demonstrated that increased levels of

¹¹ Prednisone is the generic name for glucocorticoid drugs used as anti-inflammatory agents for patients with chronic obstructive pulmonary disease. Glucocorticoid agents are used when other medications have failed to ease breathlessness (McKenry & Salerno, 1998; Smeltzer & Bare, 1996).

¹² PaO₂ refers to the "partial pressure (P) of oxygen (O₂) in the arterial blood (a)" (O'Toole, 1997, p. 208). PaO₂ levels are usually lower in patients with COPD (Smeltzer & Bare, 1996).

¹³ PaCO₂ refers to the "partial pressure (P) of carbon dioxide (CO₂) in the arterial blood (a)" (O'Toole, 1997, p. 208). PaCO₂ levels are usually elevated in patients with COPD (Smeltzer & Bare, 1996).

¹⁴ Plasma cortisol levels refers to the levels of cortisol in the plasma and may be measured following glucocorticoid therapy (McKenry & Salerno, 1998).

anxiety and not depression were associated with more severe dyspnea. In addition, increased levels of cortisol and higher levels of PCO_2 were associated with increased levels of depression.

In both studies the validity and reliability of the Visual Analogue Scale, the State Anxiety Inventory, the Brief Symptom Inventory, the Revised Symptom Checklist (SCL-90-R), and the pulmonary function tests were substantiated, and the measurement of blood gases and cortisol levels were confirmed in the second study. However, no attempt to establish the validity or reliability of the clinical measurements (respiratory rate, sighing, paradoxical breathing, depth of breathing, or use of accessory muscles), the tools most immediately available to nurses, was reported. The results related to these measures must therefore be viewed with caution. Generalisability of the findings is also questionable in view of the convenient and small sample sizes.

The research done in an attempt to understand the psychological aspect of dyspnea does clearly show a relationship between anxiety and levels of dyspnea, what theorists have called the "anxiety-dyspnea-anxiety cycle" (Carriere-Kohlman et al., 1993, p. 230). This work implies that anxiety contributes to the patient's perception of increased shortness of breath. In addition, although, no association between the severity of breathlessness and depression has been demonstrated, it is nevertheless clear that individuals with COPD, unrelated to dyspnea severity, do frequently experience reactive depression. More research is necessary to clearly understand the impact that medication therapy such as steroid administration may have on the mood of COPD sufferers. The affective contribution to a perception of more or less severe breathlessness continues to remain enigmatic. Some researchers would suggest that the

inconclusiveness of this research implores that these relationships be examined further and that we tread cautiously in our attempt to attribute responsibility for the severity of breathlessness to psychological factors. Indeed perhaps the gap in our understanding of the factors affecting the severity of this perceived symptom is more related to our imperfect understanding of how to objectively measure the experience of breathlessness (Killian, 1985; Killian & Gandevia, 1996).

Measurement of Dyspnea

Although the physiological mechanisms and the psychological components of dyspnea remain elusive, a substantial amount of research has been done in relation to the development of tools to quantify the perception of dyspnea both clinically and in the laboratory in order to facilitate physiological research and evaluate therapeutic interventions (Cockcroft, Adams, & Guz, 1989; Killian, 1985; Killian & Gandevia, 1996; Mahler & Wells, 1988). The clinical instruments developed have frequently assessed both the physiological and psychological components of the symptom. Gift (1990) classifies the available clinical assessments as "measures of activity", "self-report measures" or "multidimensional scales assessments". Work by Breslin (1992a, 1992b) and Celli and colleagues (1986, 1988) suggests that the recruitment of upper torso and chest wall muscles, muscles also used in respiration, for simple unsupported arm movements by individuals with COPD can result in dyspnea.

These instruments are intended to effectively quantify the level of perceived dyspnea and assist in the monitoring of individual progress during rehabilitation or treatment regimes (Gift, 1990; Mahler & Wells, 1988). It is particularly important to note that this work has consistently demonstrated that there is a limited reliable

relationship between the identified pathological lung changes, the physiological measurement of COPD as measured by routine spirometry¹⁵ (objective data), and the individual's experience of dyspnea and physical disability (subjective data) (Mahler et al., 1992; Mahler & Wells, 1988; Wolkove et al., 1989).

The Experience of Breathlessness

Limited research has been done to describe the subjective perceptions of COPD individuals experiencing episodes of shortness of breath. Kinsman and colleagues (1983a, 1983b), social scientists and physicians, studied individuals with either bronchitis or emphysema and developed the Bronchitis-Emphysema Symptom Checklist (BESC) as a partial attempt to bridge this knowledge gap. Initially these researchers interviewed 29 persons with chronic bronchitis and emphysema and identified 89 descriptors of symptoms which the informants identified as occurring during their breathing difficulties. The BESC, a check list of 11 symptom categories, was then constructed using cluster analysis of the 89 identified symptoms.

The BESC was subsequently validated with a group of 146 individuals consecutively admitted to a hospital in Denver, Colorado over approximately one year. The subjects had a diagnosis of either chronic bronchitis (n=51), emphysema (n=59) or a combination of both diseases (n=36). Informants were asked to rate all 89 symptoms on a five point scale according to how often each symptom occurred during remembered "periods of difficult breathing". Dyspnea and fatigue were the most frequent categories identified by participants. The categories of "sleep difficulties",

¹⁵ Spirometry is the "measurement of the breathing capacity by means of a spirometer"(O'Toole, 1997, p. 1516).

"congestion", "irritability", "anxiety", "decathexis", "helplessness/hopelessness", "poor memory", "peripheral-sensory complaints", and "alienation" were ranked by the subjects in descending order of occurrence. The researchers concluded that the classic symptoms of COPD (dyspnea and fatigue) must be viewed within the context of other psychological and physical symptoms in order for caregivers to understand and assist COPD sufferers in coping with their illness. This research did not, however, specifically deal with or discriminate between an acute exacerbation of dyspnea and the shortness of breathe tolerated by their COPD informants on an ongoing basis.

Nursing Research and the Experience of Breathlessness

Nursing research by Janson-Bjerklie et al. (1986) has also described the sensation of dyspnea. A convenient sample of 68 patients with either emphysema/bronchitis (n=26), asthma (n=23), restrictive (n=12) or pulmonary vascular (n=5) disease were interviewed once in either the hospital or their home. These subjects were asked about the physical and emotional feelings they remembered experiencing during an episode of uncomfortable breathing. This retrospective study used several instruments to measure the individual's recollection of usual and worst dyspnea, the associated sensations/symptoms both before and during dyspneic episodes, demographic variables, and individual pulmonary disease history. The instruments employed included the Dyspnea Visual Analogue Scale (DVAS), the American Thoracic Society (ATS) Grade of Breathlessness Scale (GBS), the Asthma Symptom Checklist (ASC) and the Bronchitis-Emphysema Symptom Checklist (BESC). The Profile of Moods States (POMS) was used to measure the six moods states of anxiety, depression, anger, vigour, fatigue, and confusion. Living situation and social support were

measured using the Norbeck Social Support Questionnaire (NSSQ). Validity and reliability information was included for all the above instruments. Accounts of the physical and emotional descriptions of dyspnea were obtained during a semi-structured interview.

The pattern and intensity of the dyspnea experience, as anticipated, differed across disease categories. The worst dyspnea scores for individuals with emphysema-bronchitis (\bar{x} 72.2, \pm 19.9) was very similar to persons with restrictive lung disease (\bar{x} 73.6, \pm 26.9), yet significantly less than asthmatic patients (\bar{x} 87.8, \pm 13.6; $p \geq .001$) and individuals suffering from pulmonary vascular disease (\bar{x} 82.6, \pm 18.8; $p \geq .001$). Individuals with pulmonary vascular lung disease, however, lived with the most severe usual dyspnea (\bar{x} 55, \pm 10) when compared with the other groups (asthma \bar{x} 25.3, \pm 22.6, emphysema-bronchitis \bar{x} 35.6, \pm 17.8, restrictive \bar{x} 37.3, \pm 24.8). That is, asthmatics had less usual dyspnea on a daily basis and more severe episodic dyspnea than all other disease groups while individuals with pulmonary vascular disease had more severe dyspnea on a continuous basis.

Most individuals experiencing shortness of breath characterised the experience as extremely fatiguing. Although Janson-Bjerklie et al. (1986) had hypothesised that social support would ameliorate the experience of dyspnea, they offer no explanation for the confounding finding of an increase in the severity of dyspnea as social support increased. Data from the Bronchitis-Emphysema Symptom Checklist (BESC) demonstrated that several symptoms were a concern for informants during breathing difficulties regardless of disease group. Although dyspnea was the symptom of greatest concern for all participants, the experience of fatigue, sleep disturbances and congestion were also very troublesome, and their ranking by informants varied

according to disease group. The convenient and small sample size of this research project necessitates that the results be viewed with caution.

Only one study was found which described the experience of dyspnea from the subjective perspective of the individual. Using a qualitative research approach DeVito (1990) reports on the perceptions of dyspnea and nursing behaviours during the dyspneic episode of 96 individuals in a non-acute phase of their chronic illness. The researcher, a clinical nurse specialist, regarded any contact with an individual suffering from COPD during a nine month study period as a "potential data gathering opportunity". Hence subjects were interviewed during a variety of clinical and social settings. The participants had to have experienced at least one hospitalisation with an acute exacerbation of COPD. Semi-structured interviews were used to collect data. The informants were asked to describe how they felt when they were dyspneic in the hospital and how the actions of the nurses caring for them assisted or hampered them during their breathing difficulties. A memo recording the interview was made following the researcher-informant interaction. Demographic and physiological disease data were not recorded.

Through content analysis five themes concerning dyspnea were identified. These included "fear", "helplessness", "loss of vitality", "preoccupation", and "legitimacy". DeVito reports that when informants were asked to describe their feelings during acute respiratory distress, they responded initially with recollections of fear:

It's the worst feeling in the world ... the worst way to die ... it's like smothering to death ... and you think life is coming to an end, everything is over ... it's the scariest situation ... to lose control of your breathing ... you wonder if you'll make it or not ... (p. 188)

She further concludes that expressions of helplessness expressed by the subjects

related to their inability to control their breathing during an acute exacerbation of dyspnea. Participants stated "I can't help it ... my breathing is fast, but I can't slow it down" (p. 188). The perception of "loss of vitality" was interpreted by the author as referring to the subject's perception of their shortness of breath as "a matter of life and death"—"I didn't have the power to live and breathe ... I could not hold on to life anymore ... my breathing trouble was killing me" (p. 189). In addition the researcher concludes that, for these subjects, the act of breathing during an acute event was no longer considered automatic, and during extreme distress, consumed all the informant's attention—"I could not take my mind off breathing for fear my life would end" (p. 189). DeVito also concludes that when individuals described the seriousness of their breathing difficulties they believed that their perceptions were not always taken seriously. They therefore frequently felt the need to legitimise their dyspnea—"no one knows what it's like to be short of breath ... and gasping for air" (p. 189).

Throughout the findings DeVito also presents subject quotations as illustrations of the informants' perceptions of the inappropriate actions of nurses during acute dyspnea events and possible alternative nursing behaviour. For example, when afraid "subjects expressed a desire to be cared for by knowledgeable and compassionate nurses" (p. 188). On occasion subjects reported being cared for by nurses who minimised what was to them an obviously terrifying experience, implying that they were responsible for their breathlessness, and could control their breathing if they tried. An alternative strategy offered by the subjects was for nurses to acknowledge the subjects' fear and demonstrate alternative breathing patterns. Nurses also frequently gave what subjects considered to be unsuitable directives during their respiratory distress, "try and get in control ... take deep breaths and control your breathing" or "relax and try to forget

about breathing" (p. 188), perpetuating feelings of helplessness. DeVito's research also reports that patients thought some nurses were incompetent. She writes that the subjects described some nurses as "unreliable ... and unable to judge the seriousness of their situation" (p. 190).

In conclusion, DeVito states that there are important implications from her work which can assist nurses in planning appropriate care for individuals with COPD during a dyspneic event. She suggests that acute dyspnea must be acknowledged as potentially life threatening. Nurses must understand the underlying physical and psychological aspects of this experience and be competent in assisting patients to cope with what they perceive to be a "matter of life and death" (p. 190). Although DeVito's conclusions are compelling, caution must nevertheless be exercised in the acceptance and generalisation of these findings. Some methodological limitations must be recognised. The recollections of the subjects regarding the location and timing of the event are not explicitly presented in the research report. It is impossible to determine if the subjects were referring to the emergency room care they received or the care experienced on general medicine or special respiratory care units. The data presented regarding nursing behaviour is also unsystematic and limited. Lack of demographic and disease data precludes the definition of a clear picture of the study subjects and hence the population to whom these conclusions can be generalised.

The research on the experience of breathlessness is indeed limited and has not clearly differentiated between the experience of usual shortness of breath that many COPD sufferers live with on a daily basis and the distress of an acute episode of severe dyspnea. To date the research available has demonstrated that during episodes of breathlessness, individuals experience a combination of sensations that commonly

include fatigue, sleep disturbances, congestion and anxiety. The research done by DeVito (1990) suggests that patients with dyspnea requiring hospitalisation experience acute fear and helplessness that may not adequately be understood or managed by nurses. As indicated, the weaknesses of DeVito's sampling procedures, data gathering strategies and presentation of the findings limit the generalisability of her results. Although DeVito's study represents a beginning point in the understanding of this event, a clear picture of the experience of the acute event of severe dyspnea from the perspective of the COPD sufferer is not yet available. Furthermore, no research has been done to describe either the family caregivers' or the nurses' understanding of this event.

Research Related to COPD Symptom and Dyspnea Management

Historically, because of the progressively deteriorating nature of COPD and the elusive nature of the mechanisms of the sensation, health care providers have enjoyed little success in alleviating this symptom (Anthonisen et al., 1987; Cockcroft & Heslop, 1996; Gift, 1993; Levin & Levin, 1993; Mahler, 1993; Nett & Petty, 1970; Petty, 1985b). Traditionally, in acute exacerbations of COPD, although the aetiology is unclear, physicians have linked the acute event to bacterial infection. Hence broad spectrum antibiotics have routinely been used to treat the increase in breathlessness, cough and sputum production. Unfortunately the value of antimicrobial therapy¹⁶ in these situations is unproven and remains controversial (Anthonisen et al, 1987; Nicotra et al., 1982; Tager & Speizer, 1975). Even when they are effective, these medications

¹⁶ Antimicrobial therapy involves the administration of an agent "... that kills microorganisms or suppresses their multiplication or growth" (O'Toole, 1997, p. 107).

only aid in the resolution of symptoms within 21 days, but do not assist in lessening the immediate distress of breathlessness (Anthonisen et al, 1987).

Medical therapies for the treatment of dyspnea associated with acute exacerbations of COPD remain limited. Pharmacological interventions are in the experimental stages (Burki, 1987; Mitchell-Heggs et al., 1980; Rice et al., 1987; Stark, 1988; Stark, Stark, & Russell, 1996; Stark et al., 1985). Although opiates¹⁷ have demonstrated the capacity to reduce the sensation of breathlessness, the concomitant reduction in respiratory rate and tidal volume¹⁸ are not well tolerated or appropriate for COPD sufferers in acute respiratory failure (Light et al., 1989; Manning, Mahler, & Harver, 1993). The role of oxygen therapy to reduce dyspnea during acute exacerbations of COPD is also uncertain (Gift, 1990). Recent research suggests that the use of oxygen may primarily aid in the reduction of breathlessness by stimulation of the trigeminal nerve when nasal prongs are used as the administration device, rather than by correcting hypoxemia¹⁹ (Liss & Grant, 1988).

Individual remedies traditionally used or initiated by persons suffering from severe breathlessness have also been the subject of scientific investigation. These studies have been conducted in an attempt to determine if the subjective benefit often claimed by COPD sufferers is also physiologically understandable or demonstrable. For example the use of a fan or open window is commonly requested by COPD sufferers during

¹⁷ Opiates or opiate drugs are agents usually used for pain relief. They act primarily on the central nervous system and their therapeutic actions include the alteration of perception thereby producing a calming effect. One untoward side effect is depression of the respiratory system (McKenry & Salerno, 1998).

¹⁸ Tidal volume (V_T) "... is the volume inhaled or exhaled in normal quiet breathing" (O'Toole, 1997, p, 1343).

¹⁹ Hypoxemia refers to a decrease in oxygenation of the blood and can lead to the life-threatening situation of hypoxia (O'Toole, 1997; Smeltzer & Bare, 1996).

dyspneic episodes. Individuals sitting in front of a fan frequently report a decrease in the sensation of breathlessness. Research suggests that the reported reduction in the sensation of shortness of breath is most probably because of facial nerve stimulation (Schwartzstein et al., 1987).

Pursed-lip breathing (PLB), an "... expiratory blowing against pursed lips ..." (Breslin, 1992b), is another strategy automatically initiated by certain afflicted individuals in an effort to modify the sensation of dyspnea. Studies of the use of this expiratory manoeuvre by individuals with COPD have consistently demonstrated both a decrease in respiratory rate and an increase in tidal volume (O'Donnell, 1987, 1988; Thoman, et al., 1966; Tiep et al., 1988). More recent research has shown that a complex alteration in respiratory muscle recruitment during PLB which reduces diaphragmatic fatigue while increasing the efficiency of the elastic properties of the lung and the other muscles of respiration is most likely responsible for the perception of a decrease in the work of breathing (Breslin, 1992a, 1992b).

COPD sufferers also frequently "consciously attempt to calm down" (Carrieri & Bjerklie, 1986, p. 290) as an immediate strategy for managing dyspnea (Dudley, Wermeth, & Hague, 1973). Research into the efficacy of relaxation strategies has been conducted to physiologically document the effects of this self-initiated technique. This work is also based on the anxiety-dyspnea-anxiety-cycle described by Carrieri-Kohlman and colleagues (1993); that as patients become anxious their perception of breathlessness increases, escalating the sensation of dyspnea. These studies have demonstrated that the use of relaxation strategies can significantly reduce the sensation of dyspnea, respiratory rate and levels of anxiety during non-acute phases of the illness course (Gift et al., 1992; Renfroe, 1988).

It is of interest to note that although the participants included in each of the above studies had COPD, all data was gathered during a non-acute phase of their illness. Indeed, the literature is essentially silent in regard to the effectiveness of strategies used by COPD sufferers during an acute exacerbation of their disease. In this study it will be important to explore whether COPD sufferers report the use of these techniques either at home during an acute exacerbation of dyspnea or as their condition deteriorates and they require hospitalisation. It will also be important to examine the relationship between anxiety and dyspnea (the anxiety-dyspnea-anxiety cycle) during episodes of acute breathlessness. The literature is equally sparse regarding family involvement in an acute exacerbation event. Therefore, it will also be beneficial during the course of the investigation to determine if caregivers are familiar with these procedures and use them as part of the home management plan for acute episodes of shortness of breath.

Research Related to Family Needs and COPD

As suggested above, individuals with COPD, like those with other chronic illnesses, manage their illness at home, within the context of their families. Unfortunately, as has also been discussed, the strategies for managing troubling symptoms are limited. As the disease pathology progresses families must increasingly assist these individuals with the management of their activities of daily living. We assume that during acute exacerbation events of COPD, experienced as severe incapacitating breathlessness, families aid COPD sufferers in the decision-making process and procedures to obtain medical help. The nursing literature, however, contains very little in the way of research on families and COPD, and no work has

been done to understand an acute exacerbation of COPD from the perspective of the family unit. The limited body of literature available to date will be reviewed to ascertain the state of the knowledge concerning families living with COPD.

Early research done by nurse-researchers used qualitative approaches to investigate the coping strategies of individuals living with emphysema. Fagerhaugh (1973) interviewed 22 people living with advanced disease. Her informants, 18 men and 4 women, were predominantly indigent, single, and elderly. A description of the living arrangements of three participants is provided, in part, to illustrate the importance of family and friend involvement in managing the activities of daily living. For example, one widower's support came from the manager and tenants of the apartment building in which he lived; another individual from his mates in a local pub; and a third participant depended on an elderly sister. Fagerhaugh's report omits any further demographic or specific interview information, making critical analysis of the findings impossible. Although these results must be viewed with caution, Fagerhaugh reaches the conclusion that individuals with family members/friends as substitute energy resources are more likely to cope effectively with all aspects of their disease.

Qualitative work done by Barstow (1974), again with persons living with emphysema, also concludes that family members, particularly spouses, significantly influence adjustment. In reference to her emphysemic subjects she writes:

The single most important influence on adjustment was the presence of a supportive *significant other person* (usually a wife) in the home. Her acceptance of the limitations imposed by the disease and her assumption of the responsibilities no longer assumed by the patient made his coping easier. (p. 143)

Unfortunately lack of any methodological or demographic data again prevent critical review and restrict generalisation of these findings.

The impact of chronic illness, in this case COPD, on the partner's quality of life was examined in a more recent study by Sexton and Munro (1985). This research was based on the premise that spouses play a central role in the adjustment of individuals with COPD to their chronic illness (Barstow, 1974). The study data were collected from two groups of women using a mailed questionnaire. Forty-six of the informants were wives of individuals suffering from COPD. The authors do not identify how the COPD sample was selected. The severity of the disease process experienced by the COPD husbands varied from no activity restriction due to the disease process to severely restricted activity levels. However, most of the men, 41 of the 46, had pathological lung changes which moderately, markedly or severely restricted their activity. The comparison group of 30 wives whose husbands did not have a chronic illness was recruited from church and women's groups from the same or a comparable urban area. The researchers report that although the groups were matched by years married, number of children, and employment status, the COPD wives were older and had jobs of a higher status. The definition of job status, however, is not defined. The wives' level of health was compared by the investigators using the Illness Impact Form, a tool adapted by the researchers from work done by Gallo (1977), the Subjective Stress Scale (Chapman et al., 1966), and the Life Satisfaction Index-A (Neugarten et al., 1961). They reported that wives of COPD patients enjoyed a poorer quality of life than individuals not living with chronic lung disease. These wives also reported that the worry caused by symptoms and acute exacerbations caused them their greatest concern.

Sexton and Munro (1985) nevertheless acknowledge that some limitations of the study affect generalisability of the findings. They recognise that the sample was not

a random representation of husband and wife COPD dyads and that the couples were not matched according to age or job status. The validity and reliability of the tools used are also not discussed by these authors.

The relationship between the mental health of wife caregivers of men with COPD and the type, number and nature of caregiving tasks as well as social support was investigated by Canadian nurse-researchers Cossette and Lévesque (1993). They examined the psychological well-being of a convenience cross-sectional sample of 89 French-speaking women whose husbands were diagnosed with COPD. Participants were recruited either through their husbands' visits to one of four hospital respirology clinics (71) or through a home care program (18) prior to the commencement of the service. Eight designated indicators of mental health were used. These indicators included six dimensions of psychopathology as evaluated by the Symptom Check List-90 (SCL-90) (Fortin et al., 1989); the subjective Stress Scale (Chapman et al., 1966), and the respondents' self-reported use of psychotropic²⁰ drugs. A caregiving task index developed by the researchers measured the number and type of tasks performed by the respondents and Lauzon's Family Support Index (1988) measured the adequacy of family and friend support. Validity and reliability statistics were summarised and deemed acceptable by the authors for all measurement tools except Lauzon's Family Support Index. This instrument was reported as having a low reliability score (alpha coefficient = .50).

The data were analysed using two hierarchical multiple regression analyses. Cossette and Lévesque state that their non-random cross-sectional sampling procedure precludes generalisability of results and conclusions about causality. They also assert

²⁰ Psychotropic refers to "a drug that affects the mental state" (O'Toole, 1997, p. 1341).

that the low reliability of the social support scale necessitates cautious interpretation of results. The investigators nevertheless claim that the number of caregiving tasks performed by the wife varied inversely with her mental health. Most importantly they contend that "... emotional support tasks caused the caregivers the greatest amount of distress" (p. 260) and that: "The social support received from families was perceived as more adequate than that received from friends" (p. 256). The authors further suggest that caregiver distress may be related to the wife's lack of knowledge or skill in responding to her husband's distress.

Loneliness and depression have also been identified as potential problems for both those with COPD and their caregivers. Keele-Card et al. (1993) studied a convenience sample of 30 individuals with COPD and their spouses recruited from one pulmonary clinic in a midwestern city in the U.S.A.. Participants who met the inclusion criteria and were willing to collaborate in the study were identified by clinic doctors. Twenty-three of those with COPD were men. The mean age of all the participants was 67. Eighteen of the COPD participants had "... markedly restricted activity ... nine were homebound and three required assistance with daily hygiene" (p. 247). Three scales were used to measure loneliness, depression and social support. Reliability and validity scores were reported for each instrument. The researchers claim that

... clients who were dissatisfied with their social relationships were likely to be lonely and depressed. Furthermore, the more lonely they were, the more depressed they were. (p. 250)

They also suggest that individuals with COPD were more satisfied with their social support system than were their spouses. They acknowledged that the findings from their work are not generalisable because of the small convenience sample.

In summary, the research cited suggests that families are both central to the

effective adjustment of chronically ill individuals to the lifestyle changes necessitated by COPD and personally affected by these adjustments. This research also alleges that the uncertainty of acute exacerbations of the illness are emotionally demanding and hence one of the family's most distressing and worrying tasks. However, the methodological weakness related to sampling and instrumentation require that all the findings be viewed with caution. Indeed, this review of available research clearly demonstrates that there is little knowledge concerning how individuals and families are affected by or manage COPD as a chronic illness. Furthermore no work has been done to understand the perceptions of individuals or families during this acute and recognised distressing event.

Summary

In summary, this literature review has demonstrated that COPD is a chronic progressively degenerating disease characterised by dyspnea, physical disability, anxiety, and acute exacerbations requiring hospitalisation. As described, extensive research has been done on the pathophysiology of COPD and the physiological aspects of dyspnea. To date, however, the precise physical mechanism of breathlessness is still unclear. Lack of strategies to effectively reduce the distress of uncomfortable breathing in individuals experiencing an acute exacerbation of COPD continue to present important challenges to health care providers. Further, a limited reliable relationship between the physiological measurement of COPD severity as measured by routine spirometry and the individual's experience of breathlessness and physical disability, has fuelled the investigation of the psychological aspects of dyspnea. Researchers have suggested that there is a relationship between anxiety and dyspnea,

unfortunately, however, the affective contribution to a perception of more or less severe shortness of breath continues to remain obscure. Although the limited research completed has demonstrated that individuals with COPD do experience higher levels of reactive depression, again no relationship has been shown between severity of depression and levels of breathlessness.

The research on the individual's experience of breathlessness has shown that during episodes of breathlessness informants experience a combination of sensations including anxiety, fatigue, sleep disturbances, and congestion. As discussed, this research has not differentiated between the experience of usual shortness of breath that many individuals suffering COPD live with on a daily basis and the distress experienced during an acute exacerbation of COPD. The one qualitative research study done on the individual's perception of dyspnea during hospitalisation demonstrates that individuals experience extreme fear during acute attacks of shortness of breath. This study also proposes that dyspnea is not adequately understood or managed by nurses (DeVito, 1990). The above review of COPD and family chronic illness literature also suggests that families are central to the effective adjustment of chronically ill individuals to the lifestyle changes necessitated by COPD. In particular it is intimated that families are intricately involved in the management of acute exacerbations of COPD, however, no research has been done to support this belief.

In conclusion, it is clear that acute exacerbation episodes of COPD are frequent, distressing occurrences in the illness trajectory of COPD. These events often precipitate emergency hospitalisation. Although researchers acknowledge the primary importance of managing severe breathlessness, to date, no studies have been done describing the experience of an acute exacerbation event. Furthermore, there is limited

literature addressing the experience of chronic illness as a life event for the family unit. A description of the caregiver responsibilities of nurses and family members during acute episodes of COPD is also missing from the nursing literature. Indeed, large gaps remain in the understanding of the acute event of severe dyspnea from the perspective of individuals with COPD, family caregivers and nurses. The literature review therefore confirms the need for further investigation into the needs of these individuals during acute exacerbations of COPD necessitating emergency hospitalisation.

CHAPTER 3

THEORETICAL PERSPECTIVES

At least two main conceptual threads can be identified throughout the above literature review. They are chronic illness and family. A model of chronic illness and a conceptual definition of the family constituted the theoretical underlining for this study. Several chronic illness models have been described in the literature. They provide conceptual ways of understanding the complex process of living with a chronic illness. Although the body of knowledge dealing with family research theory is less extensive, this work conceptually addresses the issues of family unit definition and family research. Of importance for this study is the fact that chronic illness models commonly describe the family unit as a central concept in their construction of the chronic illness paradigm. In this chapter, chronic illness models and family research will be discussed. The purpose of the discussion is to not only better understand these concepts but to demonstrate their appropriateness as the basis for the study's theoretical perspective.

Chronic Illness and the Family

Although care of chronic illness has long been acknowledged as one of the primary challenges facing society (Hardiker & Todd, 1982; Strauss & Glaser, 1975; Thorne, 1993), the chronic illness literature in general has only now begun to recognise the importance of the family unit (Anderson & Tomlinson, 1992; Butcher, 1994; Conrad,

1987; Gilliss, 1989a, 1989b; Gillies et al., 1989a; Goodman, 1986; Johnson, 1998; Vaughan-Cole, 1998). Leahey and Wright (1987), as family nurses, are concerned about the care of individuals and families living with long-term illness. They write:

The family system influences the course of illness in a variety of ways. Thus, the family system should be the context in which the challenges of coping with illness are resolved. Interventions target the whole family since chronic illness cannot be treated solely by a physician or nurse. (p. 55)

Conrad (1987), a medical sociologist, supports this perspective, saying:

There can be little doubt that families are pivotal in the world of illness. Families are important as interpreters, caretakers, support systems, and buffers: chronic illness can place difficult strains and new burdens on family life. Given this, it is surprising that so few researchers on the experience of illness have specifically examined the family role. (p. 15)

Although the literature contains limited research on the effects of chronic illness on the family, as previously suggested, several conceptual perspectives on chronic illness and the individual and family's adjustment to this life event have been developed (Corbin & Strauss, 1988; Dimond & Jones, 1983; Mercer, 1989; Miller, 1992; Rolland, 1987, 1988; Strauss et al., 1984; Wright & Leahey, 1987). A review of three chronic illness models will be outlined to illustrate the complex and overwhelming nature of the chronic illness experience for both the individual and the family. The examination of these frameworks is intended to both demonstrate the utility of these models in guiding research concerning the actual experiences of families living with specific chronic illnesses and describe the theoretical perspective of the present research study.

Chronic Illness

Chronic illness is medically defined as any long-term disease whose symptoms, on

an ongoing basis, interfere with an individual's ability to carry out their activities of daily living and is the result of non-reversible biological change (Dimond & Jones, 1983; Mayo, 1956; Thorne, 1993; Wright & Leahey, 1987). In chronic illness, acute exacerbations of disease requiring professional intervention and/or hospitalisation may interrupt periods of relative stability. Chronic illness is defined by social scientists as a social and psychological phenomena (Conrad, 1987; Thorne, 1993). For these researchers the involvement of families in the experience of chronic illness, although indisputable, has received limited research attention (Conrad, 1987; Gilliss et al., 1989b).

Conceptual Frameworks of Chronic Illness

The theoretical models developed to understand chronic illness organise the perception of the illness process using at least three categories. These organising structures include the use of either illness concepts, stages of illness, and/or tasks to be mastered by the individual and family. One organising strategy is generally dominant in each model. Three frameworks, prototypes of these models, are presented to illustrate the usefulness of models in understanding the complex nature of the chronic illness experience for the individual, family and caregiver. Components of these models theoretically informed the structure of the present study.

Concept model. The concept of powerlessness has been used by Miller (1992) as the central theme defining any chronic illness. The theoretical structure of illness in Miller's (1992) concept "power resources model" is based on Turk et al.'s (1986) family and individual research on illness perceptions. Using information from chronically ill individuals and health care practitioners, these researchers developed

an illness model comprised of four dimensions. These dimensions include the individual's family's perception of the seriousness of the illness, the personal responsibility related to either the development or alleviation of the disease process, the controllability of the illness by the individual or other health care agents, and the changeability or rate and degree to which symptoms vary over time—the illness trajectory. Miller suggests that the lack of control experienced by individuals and families living with a chronic illness is influenced by their interpretation of these dimensions.

She therefore advocates the enhancement of innate power resources/strategies for both ill individuals and families to facilitate their coping with the realities of long-term illness and the increased sense of powerlessness such illness inevitably creates. Seven potential power resources are identified as being available to the chronically ill individual and/or family. These include maintenance of physical strength, maximisation of psychological stamina and social support, retention of a positive self-concept, judicious use of energy resources, development of knowledge about the disease process and management and the individual's unique illness response, maintenance of motivation, and a personal belief system. These power resources are then utilised to cope with the many tasks of living with chronic illness. Miller describes 13 tasks which must be faced by the ill individual and/or their family. These tasks include maintaining a sense of normalcy, maintaining hope, maintaining control, dealing with role changes, and adjusting to altered social relationships.

Stages of illness model. A three dimensional stages of illness model of chronic illness has been developed by Rolland (1987a, 1987b). The first dimension of this theoretical framework uses the physiological basis of chronic disease to structure a

psychosocial concept of illness. This psychosocial dimension is based on four constituents: "onset", "course", "outcome", and "degree of incapacitation". The second dimension presents the life history of a long-term illness in three phases, the crisis of diagnosis, the chronic phase, and then end stage disease. The final dimension deals with the interface of the chronic illness experience within the family unit. Each dimension has a complex set of sub-dimensions reflecting the multitude of potential realities that individuals and families encounter. Rolland suggests that all individuals suffering from a chronic illness can be understood and cared for within the context of this framework. That is, knowledge of an individual's and family's status in relation to these dimensions will inform and ultimately enhance the caregiver's interventions.

Chronic illness task model. In the development of a task completion model, Strauss et al. (1984) have suggested that an understanding of a medical condition alone is not sufficient to adequately treat individuals with chronic disease. Indeed, although chronic illness affects a large portion of the population, they believe that little is known about the problems families and individuals face while living with a long-time illness (Strauss et al., 1984). Hence, these researchers have conceptualised chronic illness as a set of tasks or problems that individuals and their families face and must deal with as they live with the disease.

These tasks involve both the individual and their family regardless of the long-term disease process. They include the prevention and/or management of medical crisis, the control of symptoms, the management of treatment regimes, the prevention or adjustment to social isolation, the adaptation to the illness trajectory, the normalising of daily life, the management of funding requirements, and the confronting of psychosocial problems associated with living with a chronic disease. More specific "work"

for both the individual and family are outlined within each task. The task of managing a medical crisis is most appropriate when conceptualising the patient's and family's experience of an acute exacerbation event of COPD. This task of managing a medical crisis includes "reading the signs", "organising for crisis", "breakdown of organisation: potential and actual", and "ceding responsibility to the hospital".

A Chronic Illness Model for this Study

All three conceptual frameworks present a way of systematically understanding the very complex nature of the chronic illness experience for the individual, family, and professional caregiver. Although each paradigm is distinct in its perspective of chronic illness, the essential concepts of each model overlap. For example, all of the above frameworks acknowledge the sense of uncertainty or powerlessness faced by the chronically ill person and their family, include some idea of the temporal ordering of the chronic illness trajectory, and describe the unique challenges that must be faced by the sick individual and the family unit as they manage the illness course. However, limited empirical work has been done using these conceptual models with either individuals and/or family units.

It is therefore essential to substantiate, through research, the utility of these frameworks in clinical practice. As has been outlined, individuals with COPD frequently experience acute exacerbations of their illness. Therefore, for the purposes of this research project, Strauss and colleagues' (1984) construct of "managing medical crisis" was used to frame the research question. Based on the assumption that families rather than isolated individuals cope with a chronic illness, including the management of acute exacerbation events of long-term disease, members of the COPD

patient's family were asked to describe their perceptions of these difficult situations. However, to structure the research strategy effectively so that this question is answered in a meaningful way, a clear understanding of family and family research was also necessary.

Family

As previously discussed, the recognition of the centrality of families in the chronic illness experience unequivocally supports the need for research with affected families (Gerhardt, 1990; Gillis, 1991a). Therefore at the outset of this study it was essential to articulate a lucid definition of the family unit. This theoretical construct of the nature of the family then directed the research strategy used in understanding the impact of this illness experience on both patients and their family members. It was also essential to operationalise a theoretical conceptualisation of the family in order to determine appropriate sources of data collection (Gillis, 1991b). The following is a description of the conceptual and operational definitions of families that were used in this study. Included in the discussion are some of the implications of specific theoretical perspectives of the family and family research that I identified in the nursing literature.

For the purposes of this research study a family was theoretically defined as any individuals who mutually identified themselves as family members (Gilgun, 1992). Inclusive in this concept of family is the recognition that the persons identified may or may not be related (Friedman, 1992; Whall & Fawcett, 1991). Further these individuals may not even live together. Moreover the family unit may or may not contain children. In the context of this study, the family unit did, however, provide

caregiving functions such as protection and nourishment to the person experiencing an acute exacerbation of COPD. These individuals also acknowledged a commitment and attachment among family members that included future obligations.

Family Research

Having conceptually defined the family, the methodological issue in family research becomes one of how to effectively understand this group of individuals and obtain their perception of an illness event. That is, is the researcher to study the individual family member's perspective of an illness event and assume that a combination of these interpretations informs the total perception for the family, only study the family as a unit using group interviews, or both? Opinions on this question are varied. Some scholars have made a distinction between individual research with family members (family-related research) and research with family units (family research) (Feetham, 1991). This differentiation affects how and from whom data are collected. Based on the work of Fisher (1982) and Ransom (1984), Feetham (1991) suggests that "family-related research refers to research that focuses on relationships between family members, using data from individuals" (p. 55).

Whereas:

Family research in contrast, refers to research that focuses on the family unit as a whole. Individual family members are not considered explicitly. Rather family behaviour is taken into account. (Feetham, 1991, p. 56)

It is important to note that these writers acknowledge that family-related research and family research are of equal importance, and that both contribute to knowledge about families. Moreover, they also suggest that the crux of the issue is one of ensuring that researchers acknowledge the epistemological perspective of their work so that the

findings can be understood in the wider context of family theory (Robinson, 1995). For the purposes of this study, a family-related research perspective was adopted.

Summary

In summary, these chronic illness frameworks provided a theoretical perspective that informed the structure for systematically examining the very complex nature of the chronic illness experience for the individual and family caregivers. Although these frameworks have limited research basis, Strauss et al.'s theoretical construct outlining the tasks confronting those living with chronic illness presents an intuitively appropriate structure for developing the research method for this study. An acute exacerbation of COPD is a medical emergency which necessitates involvement of the individual and family in management strategies. Hence, interviews of the patients, family caregivers, and nurses asked to participate in this study occurred during an acute exacerbation event in order to more adequately understand their perception both of the event and the management procedures they used. Furthermore, the definition of family as those individuals identified by the individual with COPD, a concept congruent with family theory, directed study sampling. Key family informants were those individuals identified by the patient with COPD. These individuals were interviewed individually (family-related research) to obtain their perceptions of an acute exacerbation event.

CHAPTER 4

THE ANALYSIS OF STORIES

The literature review has shown that the experience of an acute episode of COPD characterised by the symptom of severe breathlessness, a symptom which incapacitates the sufferer, is poorly understood and ineffectively managed by health care providers. Furthermore a description of this illness event and its meaning from the viewpoint of the individual suffering from COPD or the caregivers attempting to offer support was not found in the literature.

Part A: Methodological Approach

The specific aim of this research therefore was to develop an understanding of the patients', family caregivers', and nurses' perceptions of the complex event of an acute exacerbation of chronic pulmonary disease characterised by incapacitating dyspnea and requiring emergency hospitalisation. The underlying assumptions of the qualitative research approach fit with the research aim of developing an understanding of this complex event from the perspective of the patient, the family caregiver, and the nurse.

My original intent was to write an ethnography that would reflect the experience of an acute exacerbation event from the perspective of patients, family caregivers, and nurses. More specifically, based primarily on the interview data of these participants during an acute episode, I intended to develop stories describing their understanding of these events. I intuitively believed that the construction of stories would be an

effective way to communicate the meanings identified in the participants' interviews. However, an initial review of the qualitative and ethnographic literature revealed that participants, during in-depth interviews, would tell "stories" in their attempt to communicate their experiences. Indeed, I discovered that there was a body of qualitative research specifically devoted to the analysis of stories in interview data. After a critical review of this literature I decided to adopt an eclectic form of narrative analysis, an extension of ethnographic inquiry in the collection and analysis of patients', family caregivers', and nurses' interview data.

In the following chapter I will briefly review the qualitative paradigm in general and then examine in more detail narrative analysis as a form of ethnographic qualitative research. The discussion related to narrative inquiry will include: a clarification of what is meant by a story in narrative analysis research; a brief description of three models of story analysis; an examination of the controversial issue of the assessment of the quality or goodness of interpretive research (and more specifically narrative analysis); and a review of the utilisation of narrative analysis in nursing research. The rationale for the use of a combined narrative theoretical framework for the analysis process will be presented, including the definitions of story as they are understood in this work. The steps in the systematic analysis process used will also be explicitly delineated. Finally, the story analysis process used in this study will be described.

Qualitative Method²¹

The goal of the qualitative research paradigm is to provide a method for "... understanding the complex world of lived experience from the point of view of those who live it" (Schwandt, 1994, p. 118). It is "meaning" that the researcher wishes to understand and then reinterpret theoretically. The increasing use of qualitative research as an important strategy for uncovering meaning across a variety of social science disciplines has fostered the development of a number of natural inquiry research methods within the qualitative paradigm itself (Bailey, 1997; Bryman & Burgess, 1994; Guba & Lincoln, 1994; Hammersley, 1989; Holloway & Wheeler, 1996; Lowenburg, 1993; Streubert & Carpenter, 1995). These developments, embodied in the language of qualitative research, are a reflection of evolutionary change; signals of the progression of the understandings of the nature of knowledge and knowledge acquisition within the paradigm itself. Classification of these meta-paradigms reflects their divergent ontological and epistemological perspectives. However, the researcher's goal within all of qualitative models, regardless of the differing approaches and methods, is to "interpret" and or "reconstruct" subjective meanings.

Initially, in the struggle to gain legitimacy in the face of established positivist or experimental principles, the interpretative strategies of determining the meaning of social behaviour, in part, portrayed the belief that social reality did exist in an objective form (Schwandt, 1994). That is, this paradigm initially suggested that knowledge was also "reality" based. The task of the qualitative researcher, therefore, was merely to describe and interpret the objectively available meanings. However, the

²¹ Segments from this section (Qualitative Method) are from "Finding your way around qualitative methods in nursing research" by P.H. Bailey, 1997, *Journal of Advanced Nursing*, 25, 18-22. Copyright 1997 by Blackwell Science Ltd.. Reprinted by permission (see Appendix C).

methods of data collection in the emerging qualitative paradigm were different. Unstructured interviews and participant observation, as opposed to mathematical formulae, were the tools employed to provide access to this reality. Over time, changes, perhaps best understood as paradigm extensions, have occurred in the understandings of the origins of social meaning. Qualitative knowing has been reconceptualised as being distinct from, rather than an extension of or precursor to, positivist inquiry. Indeed, investigators now believe that the findings of qualitative research are not objective fact but rather subjective interactive constructions which no longer need verification in the quantitative arena.

In addition, qualitative constructivist theory now suggests that reality or meaning is not only subjective in nature, but essentially the construction of participants as they interact within a social environment. Furthermore, interpretation of this reality by qualitative researchers is yet another construction. Such a philosophical shift has precipitated modifications in the focus and attention given to all components of the qualitative research process, including various data collection and analysis strategies (Atkinson & Hammersley, 1994; Schwandt, 1994).

The Language of the Qualitative Paradigm

Given the evolution of the interpretive paradigm, the initial obstacle in understanding the evolving paradigm lies in unravelling the labelling language used in the qualitative framework (Lowenberg 1993). This unravelling process is a complex task, as several terms are frequently used interchangeably in the literature referring to this research strategy. The qualitative paradigm has evolved from a relatively uncomplicated model which simply focused on the reorientation of knowledge

acquisition as description and analysis of human behaviour into a complex paradigm which includes several alternative "naturalistic" models. The development or expansion of this newer research strategy is embodied in the language of qualitative research. Although many of the terms are used generically, they are the most accurate signals of the progression of the understandings of the nature of knowledge and knowledge acquisition within the paradigm itself. In addition, the language of the qualitative paradigm, albeit used inconsistently by researchers, is the clearest reflection of the often confusing evolutionary changes occurring in practical application of research strategies (Lowenberg 1993; Thorne, 1991).

As described by Guba & Lincoln (1994), most commonly qualitative research is simultaneously referred to as natural inquiry, interpretive research, hermeneutical research, post-positivism, critical theory, and constructivism. Indeed, these labels are often used in a generic way when discussing qualitative methodologies. The historical and/or linguistic roots for these labels can be identified in the development of this paradigm over the last century, and although these words are used to refer to qualitative research in general, they can also refer to specific research perspectives or meta-paradigms within the qualitative framework (Denzin & Lincoln, 1994; Guba & Lincoln, 1994).

The term "natural inquiry" reflects the initial work done by qualitative researchers. It implies the acquisition of knowledge in a manner other than empirical research. Interpretive or hermeneutical research, terms used interchangeably with natural inquiry, simply refer to the basic nature of qualitative work, that of interpreting meanings within the context of the natural environment. All three terms have a history of use dating back to the inception of the paradigm (Denzin & Lincoln 1994).

Developmental Changes

The terms post-positivism, critical theory and constructivism reflect the gradual ontological and epistemological developmental changes within the paradigm over the last several years (Guba & Lincoln, 1994). Post-positivism, for example, which represents the earliest shift from the dominant quantitative experimental paradigm, allows scientists who understand themselves as post-modern researchers, to legitimately mix the quantitative, experimental model, and qualitative, natural inquiry perspectives, in the design of their inquiry. These researchers believe that knowledge exists in the social world and may best be understood using both interpretive and quasi-experimental methods (Guba & Lincoln, 1994). Critical theory and constructivism on the other hand, reflect later, more specific reinterpretations of natural inquiry. They focus on such ontological and epistemological concerns as the relationship of the researcher to the informant and the process of constructing meaning itself. Feminist research, a part of critical theory which values the participant as a co-researcher and narrative analysis, a form of constructivism which defines meaning as reconstructions by both the narrator and the researcher, are illustrations of these extensions.

In summary, the language of qualitative research addresses the broad concept of this newer paradigm and the specific ontological and epistemological perspectives of the meta-paradigms:

The word *qualitative* implies an emphasis on processes and meanings that are not rigorously examined, or measured (if measured at all), in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given

meaning. (Denzin & Lincoln, 1994. p. 4)

Methods of Analysis

Although the basic understandings of knowledge and its acquisition as understood by the different qualitative traditions overlap or blur, three major qualitative methods within this framework have been defined. They are generally recognised as phenomenology, grounded theory and ethnography. The researcher's goal within each of these models, regardless of the differing approaches, is to interpret subjective meanings. Narrative analysis, an extension of the ethnographic qualitative method of inquiry, was the approach used in this research study. I have included a presentation of the three major qualitative methods. Similar reviews of these main divisions (phenomenology, grounded theory, and ethnography) have been examined in more depth throughout the social science and nursing literature (Bailey, 1997; Leininger, 1985; Munhall & Oiler, 1986; Parse et al., 1985; Streubert & Carpenter, 1995; Thorne, 1991). This description of the major meta-paradigms is intended to illustrate the ontological and epistemological variation in these interpretive or constructionist strategies presently being used by social scientists, and, by providing a sense of the frameworks' historical development, locate the philosophical origins of narrative analysis within the qualitative paradigm.

Phenomenology. Phenomenology, a qualitative approach initially attributed to Edmund Husserl (Thorne, 1991), fundamentally attempts to understand "... the nature of being ..." (p. 182), the lived experience, through the window of language. "In this framework, the essential task of language is to convey information, to describe reality" (Holstein & Gubrium, 1994, p. 263). That is, the researcher using a phenomenological

approach to meaning inquiry is attuned to the subjectivity of human understanding and attempts to uncover and describe the essence of being as represented by the informant's language and behaviour in in-depth interviews. In this process the phenomenologists puts aside or "brackets" their own perspective. Extensions of the original phenomenological approach have widened this perspective to include the social interactional nature of experience in the understanding of human meanings and reality (Holstein & Gubrium, 1994; Van Manen, 1990). In all forms of this method of inquiry the researcher presents interpretations of observed lived experience.

Grounded Theory. Grounded theory as a form of naturalistic inquiry was first articulated by Glaser and Strauss (1967) in their book *The Study of Grounded Theory: Strategies for Qualitative Research*. This strategy shares the data gathering method of the other qualitative research models (Stern, 1985; Strauss, 1987). However, for these researchers "the major difference between this methodology and other approaches in qualitative research is its emphasis upon theory development" (Strauss & Corbin, 1994, p. 274). The goal of a theory development method "grounded" in actual research information was initiated, in part, by the recognition of a dearth of theoretical understandings in the science of human behaviour. The relationship of this perspective's development to the positivist paradigm is reflected in the model's initial exclusive commitment to inductive theory construction rather than hypothesis testing. Although the model's strength continues to be its systematic methodological strategies, "... constant making of comparisons ... systematic asking of generative and concept-relating questions, theoretical sampling, systematic coding procedures ..." (Strauss & Corbin, 1994, p. 274-5), recent extensions recognise "... the potential role of extant (grounded) theories and the unquestionable fact (and advantage) that trained

researchers are theoretically sensitised" (p. 277). Using grounded theory as a form of qualitative inquiry, the development or reconfirmation of theoretical constructs continues to be the fundamental task of the researcher.

Ethnography. Ethnographic research has a long history. At the beginning of this century, ethnography was used in cultural anthropology to study and describe alien societies (Atkinson, 1990; Atkinson & Hammersley, 1994; Hammersley, 1990a, 1990b; Van Maanen, 1988). For qualitative researchers "... the central aim is to understand another way of life from the native point of view" (Spradley, 1980, p. 3), an emic perspective. According to Spradley (1980), this method is concerned with developing in-depth descriptions of "... meanings of actions and events to people" (p. 5) through the primary processes of participant observation and in-depth interviewing of "key" or knowledgeable informants. Similar to phenomenology, specific methodological strategies have been developed to analyse data (Hammersley & Atkinson, 1989; Spradley, 1980).

Ethnography is a way of collecting, describing, and analysing the ways in which human beings categorise the meaning of their world. In other words, ethnography attempts to learn what knowledge people use to interpret experience and mould their behaviour within the context of their culturally constituted environment. (Aamodt, 1991, p. 41)

There has been an increasing adoption of ethnographic methods by many social scientists including those in education, health care, human geography, organisation studies, and social policy (Atkinson & Hammersley, 1994). The attempt to understand social realities in these applied disciplines using an ethnographic approach has coincided with adaptations in the traditional strategies. Depending on the research questions and cultures being examined within these disciplines, the "field" or scope of data collection, the attention to "spoken interaction" or recorded text and the

"voice" of the informant or presentation of findings privileging the "teller" rather than researcher has led to complex changes or extensions in this method. Narrative analysis, a form of research which focuses on the structure, content, and context of ethnographic interview data, is an example of an extension in the ethnographic meta-paradigm. The responsibility of interpreting meanings in all forms of ethnographic research, nevertheless, remain the purview of the researcher.

In summary, broadly defined:

Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials ... that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand (Denzin & Lincoln, 1994, p. 2).

Narrative Analysis

The fundamental ontological and epistemological assumptions of the qualitative research paradigm embody a multifaceted emic expectation. As indicated, I utilised narrative analysis as an extension of ethnographic inquiry in order to develop an understanding of the complicated experience of an acute episode of COPD. The underlying assumptions of ethnography, an interpretive or constructivist method that defines knowledge as an emic complex contextual construction of meaning, as described above, philosophically fit with my research aim to contextually understand the meaning of an acute exacerbation event from the perspective of the stories told by patients, family caregivers, and nurses when talking about their experiences with these events.

The broad underlying premise of narrative research within social science research is the belief that individuals most effectively make sense of their world and communicate these meanings by (re)constructing stories or narrating them (Bruner, 1991; Clandinin & Connelly, 1994; Coffey & Atkinson, 1996; Connelly & Clandinin, 1986; Gee, 1991; Langellier, 1989; Mattingly & Garro, 1994; Mishler, 1979, 1986, 1990; Ricoeur, 1981; Riessman, 1993; Sacks, 1986, 1992; White, 1981; Wiltshire, 1995). Narratologists believe that "... all human beings are masters of making sense of experience and the world through narrative [stories]" (Gee, 1985, p. 27). They assert that, in part, storytelling occurs "... where there has been a breach between ideal and real, self and society" (Riessman, 1993, p. 3). As Bruner (1990) suggests "... [storytelling] specialises in the forging of links between the exceptional and the ordinary" (p. 47).

According to Mattingly and Garro (1994), social scientists involved in narrative research in health care, storytelling is the ability to "... impart how an event takes on meaning for us—to convey the "double landscape" of inner and outer worlds (p. 772).

That is, individuals use stories when they

... want to understand concrete events that require relating an inner world of desire and motive to an outer world of observable actions and states of affairs ... [stories] provide a vehicle for confronting the contradictions between an individual's experience and expectations based on shared cultural models, for example, the contrast between one's history and the model of how an illness should unfold. (p. 771-2)

Definition of Story in Narrative Analysis

Before proceeding to a discussion of particular methods of narrative analysis, an examination of the predominant definitions of story used by narratologists is essential.

I have limited my discussion to personal stories as they are identified in in-depth research interviews as a form of "social discourse" rather than vast use of story in "literary discourse" (Bennett, 1986; Langellier, 1989; Mishler, 1986). A review of the social science narrative literature reveals that the conceptualisation of a common definition of story continues to be problematic for social science researchers (Langellier, 1989; Riessman, 1993; Scholes, 1980; Scholes & Kellogg, 1966; Stivers, 1993; Wiltshire, 1995). A resolution of this question, however, is central to the use of this research strategy as the definition of story adopted by the researcher ultimately determines the unit of analysis to be examined and defines the theoretical perspective from which the story meanings are understood.

Two broad definitions of story, what I have labelled "life" stories and "first-person" stories, were identified in the narrative literature. The following discussion examines these recognised story forms by outlining the two distinct definitions of story (unit of analysis), illustrating their unique theoretical perspectives, and describing their distinct methodological approaches to narrative inquiry.

Life Stories

Smith (1981), a professor of English and Communications, conceptualises story as "... most minimally and most generally ... verbal acts consisting of *someone telling someone else that something has happened*" (p. 71), suggesting that all discourse is potentially the story. Hence in the life story narrative paradigm researchers use large segments of discourse as the story or reconstruct stories from interview data (Ginsburg, 1989a, 1989b; Kleinman, 1988, 1992; Linde, 1987; Monks & Frankenberg, 1995; Personal Narratives Group, 1989a, 1989b; Polkinghorne, 1988;

Plummer, 1995; Rippere & Williams, 1985; Robinson, 1990; Sandelowski, 1991; Sandelowski, Holditch-Davis, & Harris, 1990; Wiltshire, 1995). The unit of analysis in this form of narrative inquiry consists of all available information gathered in the in-depth interviews. Data from the various sources are reconstructed during the process of analysis and take the form of a story created by the researcher. The analysis focuses on the meaning threads or themes as they relate to each other throughout the larger reconstructed discourse segment.

Story as a Limited Genre

An alternative narrative inquiry model suggests that "... 'story' is a limited genre" with specific identifiable properties (Riessman, 1993, p. 41). That is, stories, by definition, describe specific events and are inserted into longer segments of discourse as one way of transforming "knowing into telling" (Mishler, 1986, p. 147). These forms of story have a clearly recognisable beginning, middle, and end. Three forms of first-person limited story genre have been described in the literature as story units of analysis: "first-person event-specific" stories, "generic" stories and "kernel" stories.

First-person event-specific stories are the most readily recognised kind of limited story genre and are accounts that describe a specific event. Generic or habitual stories, also first-person accounts, "... tell of the *general* course of events over time, rather than what happened at a *specific* point in the past, and are constituted with verb tenses and adverbs that mark repetition and routinization" (Riessman, 1991, p. 53). A recognition of generic stories acknowledges that time is not the only component around which limited genre stories are constructed (Bennett, 1986). These stories are differentiated from other forms of talk such as reports or lists by the inclusion of an

evaluation segment (Polanyi, 1985, 1989; Riessman, 1991; Schiffin, 1994). Finally, kernel stories (Kalčík, 1975), what Viney and Bousfield (1991) describe as "stories-begun-but-not-told", are defined as ideas presented by respondents that suggest untold first-person event-specific personal stories (Connelley & Clandinin, 1990; Kermode, 1981). These accounts are inserted into the interview in the form of an abstract. These three limited story genre constitute the primary unit of analysis in this form of narrative inquiry.

Story structure. For a number of narratologists, story structure defines the boundaries and components of limited genre stories. Analysis of this element of narrative accounts ultimately reveals the function of story in the process of communicating meaning. Labov and Waletzky (1972), linguists, were pioneers in the formal techniques of linguistic analysis of oral stories. Their work is an example of how the first-person event-specific story genre is understood as a limited and clearly definable piece of talk. From their perspective, stories, structures imbedded in the course of larger speech segments, "... [recapitulate] past experience by matching a verbal sequence of clauses to the sequence of events which actually occurred (Labov & Waletzky, 1972, p. 20). In their initial research Labov and Waletzky (1972) described six components of first-person event-specific accounts. Their theoretical perspective emphasises the temporal ordering of narrative/action clauses as the major element in the definition of any story. They suggest that these clauses temporally reflect a story's reconstruction of the event being described, what Ricoeur (1981), a literary theorist, labelled "narrative time".

In Labov and Waletzky's (1972) research, temporal clauses, in conjunction with an evaluative or "so-what" clause, form the basic components and structure of all first-

person event-specific stories. Their criteria define basic story units and provide a mechanism for the locating of this particular story genre in interview texts. Labov and Waletzky suggest that complex stories can only be understood if the basic structural units of accounts are examined. Their strategy of analysing limited genre stories, although too narrow to include generic and kernel stories, has been widely incorporated as a minimal criteria for many forms of narrative analysis (Bell, 1988; Mattingly & Garro, 1994; Mishler, 1986; Riessman, 1987, 1988, 1989, 1990a, 1990b, 1991, 1993, 1994a, 1994b; Sandelowski, 1991; Stevens, 1993, 1994, 1996).

Story plot. Narratologists also suggest that for a specific piece of talk to be defined as story, it must make a point from the perspective of both the teller and the intended audience (Riessman, 1993). In addition to temporality, the concept of plot is also a common component viewed as an essential and distinctive characteristic of first-person stories (Del Vecchio Good, et al., 1994; Hunt, 1994). Bruner (1990) writes:

Perhaps its [the story's] principal property is its inherent sequentially: a narrative [story] is composed of a unique sequence of events, mental states, happenings involving human beings as characters or actors. These are its constituents. But these constituents do not, as it were, have a life or meaning of their own. Their meaning is given by their place in the overall configuration of the sequence as a whole—its plot (p. 43)

Mattingly (1994), a narratologist who studied occupational therapists, argues that plot is central to any story:

... clock time, of one thing after another, is transformed by a plot into a meaningful whole with a beginning, middle and end. Any particular event gains its meaning by its place within this narrative configuration, as a contribution to the plot. (p. 813)

In summary, therefore,

A *story* is an account of something which develops and changes. It has a plot: some kind of action which occurs over time. At a minimum, it has one temporal juncture which describes what happened and what followed. A

second temporal juncture would involve reporting what happened after that. (Paget, 1983, p. 75)

Stories and Interview Data

Information accumulated in qualitative research using interview data consists of complex forms of talk or discourse. Although some of the talk recorded during any interview includes question-and-answer dialogue and arguments, stories, as a limited genre, frequently occur as an important other form of meaning-making-talk embedded in the interview data (Riessman, 1993). When individuals are asked to relay information on how something happened to them

... the natural impulse is ... to tell a story that recounts the actions and events of interest in some kind of temporal sequence. Such a story, however, does more than simply outline a series of incidents: it places those incidents in a particular narrative [story] context, thereby giving them a particular meaning. (Tappan & Brown, 1989, p. 185)

According to Labov and Waletzky (1972), stories within interview data have essentially two functions, "referential" and "evaluation". That is, a story recounts a specific event (referential) and then, from the narrator's perspective, describes the significance of the recounted incident for the teller (evaluation).

Stories within the Discourse

Until recently these stories, as part of a section of talk in ethnographic research information, were either invisible, seen as less important data segments or digressions, eliminated from text constructed for analysis, or used as isolated sections of the deconstructed transcript (Atkinson, 1992; Good & Del Vecchio Good, 1994; Langellier, 1989; Mishler, 1986; Tappan & Brown, 1989). The relatively recent

attention given to these formerly marginalised segments of ethnographic interview data by social scientists in general is attributed, in part, to the recognition of certain problems encountered by researchers using conventional qualitative techniques in attempting to understand interview data. Narratologists postulate that the "cultural fragmentation" (Atkinson, 1992; Good & Del Vecchio, 1994) of traditional qualitative analysis ignores the meaning that is embodied in the form or structure of the story text they attempt to understand (Gee, 1991; Wiltshire, 1995).

Although the fundamental issue of the inadequacy of understanding meanings acontextually in research is not new (Mishler, 1979), traditional analysis, in its concern with content, isolates segments of text into themes essentially disregarding the construction of the total discourse. Contrastingly narrative analysis, although recognising the importance of content as a primary focus of study, contends that attention to form and content must share equal prominence in any strategy developed to understand the meanings of discourse data (Atkinson, 1992; Gee, 1991; Mishler, 1986). Indeed narratologists suggest that by decontextualizing pieces of text researchers limit, obscure or even invalidate the analysis of all meaning units.

Cultural messages are made meaningful within situations of use. A valid interpretation of text without a context is impossible ... To make general claims without knowing how the message was produced or, probably more significantly, how the audience member was situated to interpret it, is to make a gross, but interesting and often provocative error. It is the context that provides for interpretive meaning (Altheide & Johnson, 1994, p. 496).

Atkinson's (1992) work with medical students illustrates the utility of not decontextualizing texts. Atkinson, a sociologist, studied students in the third or fourth year of their training at the Edinburgh Medical School during either a medical or surgical clinical education rotation. In the initial analysis of his data he used what he

terms

... the methodological orthodoxy one finds enshrined in standard textbooks on ethnographic methods ... an approach that disaggregates the text (notes or transcripts) into a series of fragments, which are then regrouped under a series of thematic headings. In a practical sense, it is often a matter of physical fragmentation. (p. 455)

The themes he identified included "uncertainty", "patient career" and "trajectory".

Reviewing the field notes twenty years later Atkinson recognised within the text what he now perceives as stories; stories constructed by physicians in the clinical setting for pedagogical purposes. At this point in time he proposes that the clinical context more than the actual events moulded the dialogue. That is, the cultural/contextual expectations of the clinical setting were the important factors that shaped the construction of the dialogues spoken by the physicians. He writes:

... what now concerns me is the nature of these products as *texts*, and the nature of how the "texts" they report (and distort) and comment on. In particular, what now strikes me is the extent to which the scenes and actions that are represented, or hinted at, there display a variety of spoken performances largely, but not exclusively, by the clinical teachers. What now engages my attention, then, is the *rhetoric* of medical accounts and presentations rather than the fragmenting episodes into small shreds and patches. (p. 460)

The Context of Stories

In order to understand more adequately the meanings created by informants, some narratologists suggest that stories must be viewed not only as intact segments but also within the social and cultural context of the creation. As outlined by Smith (1981), "... no narrative version can be independent of a particular teller and occasion of telling" (p. 215). Riessman, a Professor of Sociology and Social Work, addresses another aspect of the relevance of context in her book *Narrative Analysis* (Riessman, 1993).

She argues that not only is the context in which individuals construct stories an essential element in the understanding of their intended meaning, but also that the meaning of the total discourse is influenced by the way these stories are inserted into discourse. That is, an individual's use of stories in their creation of a total piece of talk must be recognised as an integral element in the construction of meaning and hence critiqued in the analytical process (Bell, 1988). Informants insert stories into a discourse to illustrate or emphasise their perspective of reality (Jefferson, 1978). An acceptance of this strategy as a legitimate meaning making method used in story segments of discourse further necessitates that the structure of the total interview be analysed (Riessman, 1993).

Models of Narrative Analysis

Narratologists contend that story segments of qualitative interviews can be systematically analysed "... to generate meaningful and promising findings" (Mishler, 1986, p. 76). As already suggested, although the development of narrative analysis within social science is in its formative stages (Manning & Cullum-Swan, 1994; Wiltshire, 1995), several researchers have described analysing models (Agar & Hobbs, 1982, 1983; Bell, 1988; Gee, 1991; Riessman, 1993). A review of the literature suggests that these analytical models are driven by various underlying theoretical understandings of discourse related to the structure of stories, the context of their telling and referential meanings (Mishler, 1986). In this section analytical models will be discussed with respect to these theoretical underpinnings.

Story Structure

An understanding of story meanings and function for some researchers centres on an evaluation of the form or structure of the story within a discourse. The work of Labov and Waletzky (1972) is an example of this perspective. Their work suggests that the presence of specific narrative structures define story (the unit of analysis) and allow for the interpretation of meaning once the boundaries of the story are determined. As already discussed, their definition of story essentially involves the recounting and evaluation of specific events. Although their structural analysis model does not address the interactive nature of story construction, the clarity and simplicity of the definition of story segments embodied in this approach have facilitated its general acceptance and subsequent use in combination with other narrative analysis models by a number of researchers (Bell, 1988; Bennett, 1986; Riessman, 1993; Stevens, 1993, 1994, 1996).

Story Meaning

Alternative narrative analysis models, are essentially grounded on a theory of referential meanings. By referential meaning these researchers are referring to "... content—expressed through 'themes' and their relations to each other ..." (Mishler, 1986, p. 87) within story segments. For example, Agar and Hobbs (1982, 1983), also linguists, in their work with artificial intelligence developed a model based on the concept of referential meaning. For these researchers the referential meaning or content themes identified in stories, conceived as coherence, relate to three aspects of interview text: the overall meaning plan of the interview data, "global coherence"; individual segments of the story, "local coherence", and specific themes or threads

which reoccur throughout any discourse that contains stories, "thematic coherence". These authors present a method for microanalysis of a discourse illustrating the identification of these themes within and between stories, and suggest that use of this systematic methodology strengthens the credibility of interpretive narrative analysis.

However, although referential or content frameworks as outlined by Agar and Hobbs (1982) usually give specific direction as to text analysis, the actual construct for abstracting meaning from any given story is not presented in an explicit manner (Mishler, 1986). That is, narratologists using this method do not routinely describe the theoretical framework informing their meaning analysis (Riessman, 1993). Rather, they appear to interpret story meaning on inferred or intuitive cultural norms assumed to exist between researcher and storyteller, and a clear outline of this meaning making process is not visible. Further, although a referential or meaning model may, as acknowledged by Agar and Hobbs (1982), address textual structure as a secondary concern, this method does not ordinarily adequately discuss the inherent interactional nature of qualitative research (Mishler, 1986; Riessman, 1993).

Story Context

A final group of narrative analysis models is based on the theoretical assumption that context and interaction are central in the construction of narrative meanings (Bell, 1988; Gee, 1985, 1986, 1990, 1991; Gee, Michaels, & O'Connor, 1992; Ginsburg, 1989a; Mishler, 1986; Paget, 1983): what Hammersley and Atkinson (1989) refer to in ethnographic inquiry as "reflexivity". Story data are interpreted in the context of a teller and hearer. The underlying theoretical supposition of these analytical frameworks is that a narrative or story is mutually constructed in any interview

situation and texts used in analysis of verbal interview data must therefore contain contextual information that constitutes a substantive part of the analytical review. Social scientists who employ this analytic strategy recognise that as interviewers they are inextricably part of story construction and consequentially include their interview questions in the presentation of story segments that are transcribed as closely as possible to the actual speech, retaining all the non-lexical utterances, false starts and intonation changes (Bell, 1988; Gee, 1985, 1986, 1990, 1991; Mishler, 1986; Paget, 1983). These researchers thereby clearly acknowledge their unique contribution to the construction of the narrative and the subsequent meaning units in the imbedded stories, and allow the reader to evaluate the joint construction process. As Bell (1988) writes "this level of detail helps to display how the story emerges, and how the narrator and listener construct it together" (p. 103).

Discourse in Stories

Some narrative analysts also suggest that to adequately understand the meaning of stories as a limited genre, the discourse within these accounts must also be examined (Antaki, 1994; Bennett, 1986; Gee et al., 1992; Labov, 1972, 1982; Labov & Fanshel, 1977; Labov & Waletzky, 1972). By discourse they are referring, in part, to the discursive and rhetorical devices used by individuals in the reconstruction of events: i.e., metaphors, stylistic devices such as idea repetition, and rhetorical strategies such as direct quotations, word and phrase repetition, and variations in the tone or form of story presentation (Antaki, 1994; Edwards, 1991; Edwards & Potter, 1992; Lakoff & Johnson, 1980; Potter, Edwards & Wetherell, 1993; Potter & Wetherell, 1987; Sontag, 1978, 1988; Widdicombe, 1993). Individuals, when telling

a story intentionally or subconsciously employ these discursive and rhetorical strategies to clarify or strengthen the meaning they are intending to communicate. Examination of this aspect of stories assists in more adequately understanding the structure, meaning, and function of specific stories, and also makes explicit the elements that determine that an account is a textual structure that effectively communicates meaning (Bennett, 1986).

In summary, these narrative models address structure, meaning, and context in more or less distinct models of story analysis. More recent work by Gee (1991), suggests that narratologists, although epistemologically divergent, are beginning to recognise all three components as important parts of any analytic framework and as such are beginning to integrate all three perspectives into their work. For Gee (1991)

... the discourse structure of a text (in the current discussion, a narrative text [story]), at a variety of different levels, functions to set up a series of *cues* or, better put, *interpretive questions*. These questions must be answered by any acceptable interpretation, but the answers given are constrained by the questions asked. There will, of course, usually be several acceptable answers, differing by the sorts of contextual knowledge the interpreter brings to the job of interpretation. But many answers are ruled out by the structure of the text. (p. 16)

Questions regarding the trustworthiness of this analytical paradigm, in particular narrative analysis, will now be addressed.

Evaluation of Quality²²

The concept of quality in qualitative research has been referred to in a variety of

²² Segments from this section (Evaluation of Quality) are from "Assuring quality in narrative analysis" by P.H. Bailey, 1996, *The Western Journal of Nursing Research*, 18(2), 186-194. Copyright 1986 by Sage Publications, Inc., Corwin Press, Inc.. Reprinted by permission (see Appendix C).

ways. The alternative terms used by interpretive researchers include "trustworthiness", "credibility", "authenticity", and "goodness". Traditionally, the quality of any research findings has been determined by critiquing the validity and reliability of the research process. That is:

Until recently ... valid research was distinguished from invalid research in terms of the extent to which the proper procedures were properly applied ... For empiricism a judgement about the quality of research was in effect a judgement about methodology; valid studies were procedurally correct, inept studies were procedurally flawed. (Smith, 1990, pp. 168-9)

For researchers engaged in qualitative work where methods are variable and flexible, and the researcher the essential research tool, the application of these concepts has historically been regarded as problematic (Brink, 1987, 1991; Clarke, 1995; Jansen & Peshkin, 1992; Krefting, 1990). In the early 1980's interpretive researchers nevertheless continued to search for and defend against what they labelled "sources of error" as articulated by the positivist model. Indeed "a common criticism directed at so-called qualitative investigation [was] that it fails to adhere to canons of validity and reliability" (LeCompte & Goetz, 1982, p. 31). This early literature, however, revealed the uneasy realization that the concepts of validity (objective truth) and reliability (the stability of findings over time), as understood from the positivist perspective, were somehow inappropriate and inadequate when applied to interpretive research (Lincoln & Guba, 1985; Mishler, 1990).

Several scholars have addressed these concerns in an effort to resolve or at least clarify the quality dilemma (Agar, 1986; Brink, 1987; Guba & Lincoln, 1989; Hammersley, 1992; Janesick, 1994; Lincoln, 1990; Lincoln & Guba, 1985; Marshal, 1990; Mishler, 1986, 1990; Morse, 1994a; Paget, 1983; Polkinghorne, 1988; Riessman, 1993; Sandelowski, 1993; Smith, 1990). An initial clarifying strategy for

some qualitative scientists has been to make the interpretive process more explicit. For example, Agar (1986), an ethnographer, in an attempt to enhance possible communication between positivist and interpretive scientists, outlined a language structure for ethnography which relabels the ethnographic process of data analysis in a more explicit and systematic manner. "Strips" are defined as the basic data units and the development of "schema" denotes the evolving frame used to determine "meaning". "Resolution" describes the process of understanding "breakdowns" between traditions and has as its objective "coherence". His goal was to illustrate the methodological rigor of ethnography in understandable and consistent terms and hence indirectly address the issue of validity and reliability—quality within this paradigm. Although his approach assists in illustrating the increasingly systematic nature of qualitative data analysis, it does not either directly address the philosophical differences in the paradigms or resolve the credibility debate.

Lincoln and Guba (1985), educational researchers, in their original consideration of this issue of quality, further illustrate the unsatisfactory philosophical entanglement of the two paradigms. These researchers substituted what they proposed as equivalent terms from the positivistic to the interpretive paradigm. Their "trustworthiness" criteria, although acknowledging the superiority of the established positivist rigor criteria, were an attempt at ensuring some scientific acceptability of qualitative findings. Therefore, in their model "internal validity" was replaced with "credibility", "external validity" by "transferability", "reliability" by "dependability", and "objectivity" by "confirmability" (p. 300).

In answer to the question "how can we assess the validity of a narrative interpretation?" (Mishler, 1986, p. 108), the early writing of Mishler (1986) and

Polkinghorne (1988), narratologists defending interpretive methodology, again demonstrates that most qualitative researchers initially approached the issue from a very positivistic perspective. Polkinghorne (1988), a clinical psychologist engaged in narrative analysis, begins his discussion of the evaluation of quality in narrative inquiry using three of the concepts central to the quantitative/positivistic paradigm: validity, reliability and significance. He suggests that the quality of interpretive research using stories can be determined when the same terms used by the "received" tradition are merely understood as broader concepts.

For Polkinghorne (1988), quality in narrative findings can be evaluated by simply employing alternate more common-use meanings for these ideas. He argues therefore, that validity in narrative analysis should be understood as "verisimilitude", "... results that have the appearance of truth or reality" (p. 176), and are "well grounded and supportable". In addition, reliability refers not to reproducibility of a similar "story" on a subsequent occasion, but rather the "dependability" of the one-time narrative data base. Finally, he suggests that significance should be measured by determining if the results of narrative analysis are "meaningful" or "important" rather than referring to the strength of statistical calculations. This redefinition of terms conventionally used in quantitative research, however, does not explicitly address the epistemological differences inherent in the qualitative paradigm. The search for meaning rather than truth is not discussed, and the discussion therefore, further illustrates the inadequate coalescing of the two paradigms.

New Ways of Defining Quality in Qualitative Research

In recent years an extensive dialogue concerning the value or quality of qualitative

research has occurred. As a result, alternative ways of determining the quality of knowledge generated within the interpretive paradigm, based on a recognition of paradigmatic epistemological differences, have emerged. The language of this dialogue reflects the evolution in the understanding of this concern. In this literature research findings are now evaluated for "trustworthiness", "credibility", "authenticity", and/or "goodness". This work reflects a fresh understanding with respect to both validity and reliability within the community of qualitative researchers.

It is now recognized that the concept of validity when employed within the interpretive paradigm, must not just be redefined but rather reconceptualised. Lincoln and Guba (Lincoln, 1990) now state that the "trustworthiness" criteria which they originally developed "... had their foundation in concerns indigenous to the conventional, or positivist, paradigm" (p. 71), and were therefore inappropriate. These researchers subsequently reconceptualised the "trustworthiness" criteria which were based on the ontology of positivism (truth), with "authenticity" criteria based on the relativism of the qualitative model (Lincoln, 1990). Their authenticity criteria, in part, now reflect "... the need for such inquiries to express multiple, socially constructed, and often conflicting realities" (Lincoln, 1990, 72). Explicit authenticity criteria, however, are still not identified. More recently the term goodness has been used by qualitative researchers in debating the nature of and/or need for criteria to be used to differentiate between valid and invalid qualitative research (Heshusius, 1990). As the qualitative paradigm matures, the issue of quality assurance and evaluation continues to be unresolved.

Quality in Narrative Analysis

The recent writing of researchers doing narrative analysis reflects the evolving understanding and complexity of the quality issue (Mishler's 1990; Riessman, 1993). Narratologists refer to the reconceptualization of validity/reliability within the interpretive/constructionist paradigm as a "process". For these researchers this reformulation using terms such as "trustworthiness" and "credibility", changes validity from an objective reality to the "process of confirmation/validation".

Validation, the process through which we make claims for the trustworthiness of our interpretations, is the critical issue. "Trustworthiness" not "truth" is a key semantic difference: The latter assumes an objective reality, whereas the former moves the process into the social world. (Riessman, 1993, p. 65)

That is, the researcher allows the readers/colleagues to judge the authenticity/trustworthiness of her/his work. This process is not merely the employment of two or more raters during the analysis of data to ensure equivalence (Brink, 1987) or "member checks" to affirm the researcher's interpretation (Riessman, 1993). Rather, it is important to understand that, to date, in narrative analysis, the predominant strategy of the confirmation or validation activity is simply to make the research process visible (Polkinghorne, 1988; Mishler, 1990; Riessman, 1993; Sandelowski, 1993).

For narratologists this "making visible process" does not excuse them from systematic analysis of their data, but rather places their work in the realm of scholarship by allowing systematic scrutiny (Mishler, 1990). That is, credible, valuable narrative interpretation presents

... data in the form of the texts used in the analysis, with full transcripts and tapes that can be made available to other researchers; ... methods that transformed the texts into findings; and ... the direct linkages shown between data, findings, and interpretation. (Mishler, 1990, p. 429).

The presentation of data in this manner enhances the authenticity of the findings by not privileging the researcher as sole interpreter. Indeed, there is not just one correct interpretation of the structures, meanings or context of stories. Moreover, there is no specific set of rules which if followed confer credibility, rather:

Trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable; it is less a matter of claiming to be right than to have practised good science. (Sandelowski, 1993, p. 2)

According to Riessman (1993), for researchers concerned with stories imbedded in longer discourse, retranscription of specific narrative sections of the text, once they are identified, is necessary. After the units for analysis are identified, they are individually and collectively analysed according to the selected narrative analysis method. For Riessman (1993) the final phase in the narrative analysis process is determining how the selected story sections of the text and their interpretation will be represented for the reader. This process is again guided by the theoretical perspective of the researcher. Text in both detailed and tidied forms is conventionally included in tandem with the researcher's interpretation of narrative meanings. Inclusion of entire stories in both core and unabridged forms of reconstruction to illustrate the interpretive process serves at least two functions. The presentation of large segments of unreduced and reconstructed text first of all allows the reader to hear the voices of the participants as well as evaluate the interpretive process and meanings presented by the researcher.

In summary, the evaluation of quality in qualitative research and more specifically narrative analysis, must now be understood using a reconceptualization of the concept of validity as the process of validation. The validation concerns identified in the

narrative nursing research literature include the need to clearly outline the research methodology and present the findings so that fellow researchers and consumers may participate in the evaluation of the researcher's analysis. Finally, to ensure the importance of narrative work, strategies must be developed to overcome the obstacles of adequately incorporating these requirements into professional journal reports (Polit & Hungler, 1989).

Validation is then understood as a

...process(es) through which we make claims for and evaluate the trustworthiness' of reported observations, interpretations and generalisations. (Mishler, 1990, p. 419)

In addition, scholars now acknowledge that the traditional notions of reliability do not apply to interpretive research in general (Lincoln, 1990) and narrative work specifically (Chinn, 1994; Riessman, 1993; Vezeau, 1994). Narratives, as reconstructions of past events, change with both the passage of time and the context of the telling. Replicability is therefore an inappropriate form of validation. Although qualitative methodology is still in the formative stages (Guba & Lincoln, 1994), this new conceptualisation focusing on validation is now possible because of the evolutionary development or maturing of the interpretive perspective.

Qualitative scientists are now able to articulate that since the positivist and interpretive paradigms are epistemologically divergent, the transfer of credibility criteria from one perspective to the other is not automatic or even reasonable. That is, the experimental model presupposes an objective and measurable reality or truth, whereas the interpretive approach is interested not in truth but meaning (Chinn, 1994; Personal Narratives Group, 1989c). Indeed for the interpretive researcher using

narrative analysis, "the historical truth of an individual's account is not the primary issue" (Riessman, 1993, p. 64). It is understood that participants reconstruct reality in giving meaning to their lives. As Williams (1984) writes, these "... narrative reconstructions [are] attempts to account for and repair breaks in the social order" (p. 193). They are meaning making events, interpreted by the teller, then the analyst. It is the reconstruction of meaning, not truth, that the researcher wishes to understand and then reinterpret theoretically.

Transcription

The process of transcription of the audiotapes into a textual data base for narrative analysis and story selection are central in this quest for quality in narrative inquiry. Researchers across qualitative theoretical perspectives acknowledge that the task of creating written text is critical to the success and quality of the analytic process (Silverman, 1993). Two crucial assumptions regarding the process of transcription recognised by narratologists are that "... transcriptions are the researcher's data" and that "... transcription is a selective process reflecting theoretical goals and definitions" (Ochs, 1979, p. 44). In narrative analysis, transcription involves a transformation or reconstruction of the original speech act from an oral into a written form. Consequently decisions must be made about the inclusion of interviewer questions and the style of transcription.

In the construction of the data base, a representation of the original talk, researchers must therefore be aware of the theoretical basis for the transcription process they select. Hence, all transcribed text will of necessity be selectively incomplete. In addition researchers recognise that to adequately analyse narrative data,

tape recorded interviews must be available (Mishler, 1986; Sandelowski, 1991). To allow for alternate interpretations of the text by readers, it is also essential to have a standard form of speech representation. The retention of important aspects of oral text such as pitch, pauses, and non-lexical expressions is generally necessary. For most narratologists these components of oral speech provide important meaning or interpretive clues (Gee, 1991).

For example, Gee (1991), a linguist, who views interview datum as oral speech acts, believes that the transformation to written text demands that intense care be taken to ensure as accurate a representation as possible is created of all aspects of the oral reality. This involves the inclusion of changes in pace, pitch, and breaks in talk such as pauses. Transcription of the text in a more general way may be appropriate for investigators doing life story narrative analysis (Ginsburg, 1990). Regardless of the transcription process adopted, the methodical preparation of oral data as text and the subsequent systematic review of the transcript is the critical first part of the analysis process that ensures quality.

Qualitative Nursing Research

The formal recognition in nursing of the qualitative paradigm as an acceptable research perspective has occurred within the last decade (Ayres & Poirier, 1996; Field & Morse, 1985; Leininger, 1985; Morse, 1989, 1994b; Munhall & Oiler, 1986). Nurses have only recently assumed a research role and nurse-researchers, mainly schooled in the positivistic tradition, have, until the last few years, been hesitant to embrace qualitative methods. The traditional perception of the controversial validity of this alternative research framework by the larger scientific essentially positivistic

community may, in part, account for this reluctance. A more recent increase in the use of the interpretive or constructionist research strategies by nurses-researchers coincides with the general increasing acceptance of the qualitative paradigm as a viable model for social science research. Nurse-scientists also now recognise

... the philosophical fit of the qualitative paradigm with the values and beliefs that have long characterised nursing practice ... The hearty emergence of qualitative research in nursing can be attributed to the desire to develop knowledge in the discipline in accord with the practice that such knowledge serves. (Oiler Boyd, 1993, p. 9)

The main traditions of qualitative research, phenomenology, grounded theory, and ethnology have all been used to guide nursing investigations (Aamodt, 1991; Anderson, 1989; Chenitz & Swanson, 1986). Nurse-researchers continue nevertheless to express great concern regarding the preservation of methodological rigor within this alternative paradigm (Morse, 1989; Sandelowski, 1993; Thorne, 1991). For some researchers the paranoia over validity and reliability has translated into methodological "inflexibility" (Morse, 1989; Sandelowski, 1993). For others the adoption of qualitative methods by nurse-scientists is seen as a unique window of opportunity (Oiler Boyd, 1993; Sandelowski, 1991). That is, the use of these developing qualitative strategies in the study of the broad field of nursing practice allows for unique extensions of these frameworks within the context of nursing research. Indeed, narrative analysis is viewed by some nurse-scientists as one of these exciting extensions (Sandelowski, 1991; Stevens, 1993, 1994, 1996; Tilley, 1995).

The Use of Narrative in Nursing

The practice of storytelling as a means of transmitting ideas, however, is not new in the nursing literature. "Nursing narratives" or the retelling of often poignant

nursing/patient experiences, has frequently been utilised as a user-friendly form of communicating concepts or ideas in both formal and informal nursing settings (Boykin & Schoenhofer, 1991; Maeve, 1994; Parker, 1990; Wiltshire, 1995). *A Way with Words* (McGarvey & Diekelmann, 1992), a personal story of "[a]ttending the dying" (p. 43); or *A Broken Promise* (Fowler, 1992), an intimate account about learning from a mistake, are classic examples of numerous first-person nurse-patient life stories that can be found throughout the nursing literature. Conventionally the function of such stories has been to convey a fundamental practice truth or illustrate a practice dilemma. It has been assumed that the audience, frequently the neophyte practitioner, learns best from this kind of story presentation. Although these stories are on occasion accompanied by a commentary indicating the intended interpretation (see McGarvey & Diekelmann, 1992), a theoretical process of analysis is not offered.

A recent increase in the formalised use of stories in nursing education is another example of the growing belief that storied accounts may convey complex information more effectively than alternate behaviour model methods (Bergum, 1991; Bowers & Moore, 1997; Dieklemann, 1991; Parker, 1990; Picard, 1991; Rittman, 1992). For example, Rittman, a nurse-researcher, uses stories in a preceptor education program to help individuals "... understand their work as preceptors and ... uncover their skilled practices" (p. 370). She believes that the telling and sharing of personal work-related stories within the context of the interpretive paradigm, a form of reflective practice, permits the participants an emic understanding of their own functioning. As a teaching-learning strategy in this particular educational program, preceptor stories are read and reviewed by the teachers and practitioners during classroom group sessions in order to illustrate skilled behaviour. Rittman includes several story

segments in her article describing the program, however, a theoretical process of critiquing or evaluating these stories is not outlined.

In contrast to the extensive use of storytelling in education, the use of stories in nursing research is just beginning (Gadow, 1995; Geanellos, 1995; Sandelowski, 1991; Stevens, 1993, 1994, 1996; Stevens, Hall, & Meleis, 1992; Vezeau, 1994; Walker, 1995; Whiltshire, 1995). An ever increasing number of studies reporting some association with narrative inquiry as an approach to either data collection or analysis can be found in the nursing research literature. Narrative inquiry has been used by nurses to examine a variety of nursing situations including studies of the ambiguities experienced by infertile couples (Sandelowski et al., 1990); nurses' experiences and work life (Benner, 1991; Benner, Tanner, & Chesla, 1992; Bowers & Moore, 1997; Fenton & Brykczynski, 1993; Tanner et al., 1993; Vezeau, 1993); HIV and lesbian health care issues (Hall, 1994; Stevens, 1993, 1994, 1996; Stewart, 1994); the meaning of long-term care (Crisp, 1995; Heikkinen, 1993; Heliker, 1997); perceptions of schizophrenic patients and their carers (Hellizen, Norberg, & Sandman, 1995); ethical issues in nursing care (Cooper, 1991; Udén, et al., 1992); children's health (Knafl, 1995); cancer nursing (Mathieson & Stam, 1995); and issues related to women's health (Facione & Dodd, 1995; Meleis et al., 1994).

The nursing studies using a narrative analysis identified in the literature fit into the two story groups previously described, life or illness stories and limited story genres. However, important issues related to the use of narrative inquiry were identified in both groups of studies. For example, in a number of the above studies there is limited reference to narrative theory or the manner in which an identified narrative model drives the analysis process. Although the authors initially describe the importance for

informants of storytelling in the construction of meaning, few of the nurse-researchers clearly define what they mean by story or narrative as it is to be understood in their work. The basic constituents of narrative analysis, including a critique of the structure or form of story, referential meanings in and between stories, and the interactional nature of the narrative construction process are frequently not discussed. Rather, the analysis process generally focuses on the content or themes identified within the interview data.

Further, the presentation of the research findings in the nurses' work frequently "privileges" the researcher's interpretation. For example, basic validation strategies, including a clear outline of each step of the reconstruction process and the presentation of original "untidied" data normally present in narrative analysis, are missing (Mishler, 1986; Riessman, 1993). Hence the opportunity for the reader to validate the interpretations or draw alternate conclusions is forfeited. As Wiltshire (1995) suggests, regardless of the nurse-researcher's definition of story,

It should not be assumed that a narrative [story] form gives direct and unproblematic access either to the patient's condition, or the nurse's practice knowledge. One cannot think of a narrative [story] simply as a transparent window opening onto new epistemological realms of material and understanding. Windows have frames, and window panes refract and reflect. (p. 77)

Part B: Development of a Framework for Analysis

After an extensive review of the narrative literature described above, I decided to use an eclectic narrative analysis approach in my examination of the interview data provided by the respondents regarding an acute episode of COPD. Although, as discussed, a number of theoretical analysis models exist, they do not provide explicit

easy to follow "how-to-do-it" implementation strategies. Hence, it was necessary to develop an analysis process that adequately identified and addressed the individual story structures in the data, the interpretive meanings within each story and across interviews, and the interactive nature of the construction of these stories.

To accomplish this task, and building on the work of other nurse researchers who have employed a form of narrative inquiry (Sandelowski, 1991; Stevens, 1993, 1994, 1996), I initially combined two narrative models in my analysis process. These included Labov and Waletzky's (1972) functional analysis model of individual stories and Agar and Hobbs' (1982, 1983) strategy of identifying story coherence across interviews (Bell, 1988; Mishler, 1986; Riessman, 1993). In addition, I addressed discourse within the identified stories: i.e., the discursive and rhetorical devices used by individuals in the reconstruction of their accounts (Bennett, 1986). This combination of theoretical models allowed me to clearly define limited genre story as the unit of analysis within the analysis process, examine story meanings within the context of this particular illness experience, and describe the discursive strategies employed by study participants across story genre.

The Unit of Analysis

My first task in the analysis process was to clearly define what would be understood by story within this study. Use of Labov and Waletzky's (1972) functional analysis model partially facilitated resolution of this issue. As previously described, this framework outlines a precise definition of story and also delineates a process for the identification of first-person event-specific stories within interview discourse. Hence, after a preliminary review of the interview data, I decided to designate first-

person event-specific stories, as defined by Labov and Waletzky's (1972) work, as the initial unit of analysis for determining the function of stories in uncovering the meaning of an acute exacerbation event. In accordance with the work of these researchers, I began my analysis by defining stories as first-person event-specific accounts with clear beginnings and endings.

First-person Event-Specific Stories

As indicated above, the story unit as defined by Labov and Waletzky's (1972) theoretical model includes specific story properties or elements potentially identifiable in each narrative structure that "recreate[s]" a discrete moment in time (Riessman, 1990, p. 1195). These elements, constituting what Labov and Waletzky described as a complete story, include: an abstract or plot summary; an orientation or introduction of place, time, characters, and situation; a complicating action or focus of the story; the meaning, point or interpretation of the story by the teller; a resolution or result of the action or events of the story; and a coda or story ending where both the narrator and listener are returned to the present. According to these authors an incomplete or "minimal" story needed to include a complicating action and evaluation section. For the purposes of the analysis I utilised the following detailed understanding of the structural elements of limited genre stories as defined by Labov (1972) when identifying and analysing first-person event-specific, generic, and kernel stories.

Abstract. The telling of a story may begin with a brief outline of the story, a plot summary, or "... a statement of the general proposition that the narrative will exemplify" (Labov & Fanshel, 1977, pp. 105-6). This element "... hints at and summarise(s) but does not fully explicate" the story itself (Riessman, 1988, p. 160).

On occasion the storyteller may use a generic story as the abstract. In addition, either the abstract or orientation elements assist in defining the beginning boundary of a story.

Orientation. The orientation element performs part of the referential function of an account by identifying the events around which the story will be based. Although these phrases are usually placed at the beginning of the account, their position in the story is not fixed. As "free" phrases (Labov, 1972; Labov & Waletzky, 1972), they introduce the place, time, characters, and situation of the story (Labov & Fanshel, 1977). The orientation phrases can take the form of a generic story. In addition, the orientation sections of explanatory stories may be longer in order to facilitate the comprehension of these kinds of accounts.

Complicating action. The complicating action is the "...defining characteristic[s] of any narrative" (Mishler, 1986, p. 79). It embodies the plot of the account and further fulfils the referential function of a story. According to Labov & Waletzky (1972), the storyteller intentionally orders these phrases to reflect her/his perception of how the events actually occurred. These researchers would suggest that the complicating action provides a temporal retelling or portrayal of specific past events by the narrator. This temporal structure is created by the actual or implied use of the conjunction "then" between two phrases. Phrases separated by this conjunction are connected by what Labov and Waletzky define as a "temporal juncture" (1972).

Therefore these narrative clauses, by definition, have a fixed temporal order. In fact, although the presented narrative may or may not "match the temporal sequence of that experience", a reordering of these clauses within a story would unacceptably alter the "... original semantic interpretation" (Labov & Waletzky, 1972, p. 25).

Narrative clauses are not necessarily "contiguous" (Labov & Waletzky, 1972), and can be separated by any of the other narrative elements. However, they generally occur after the orientation clauses and precede the resolution segment of the story. Although these associated phrases may be linked causally, the researcher must be aware that the review of past events may present merely "the illusion of causality" (Connelly & Clandinin, 1990; Crites, 1971).

Evaluation. The evaluation section of a story explicates the "point" or "significance" of the account for the teller (Labov & Waletzky, 1972). It is what Labov and Waletzky describe as "... the soul of narrative" (Mishler, 1986, p. 81). Evaluation phrases are used to "... reveal the attitude of the narrator towards the narrative [story] by emphasizing the relative importance of some narrative units as opposed to others" (Labov & Waletzky, 1972, p. 37). They express the storyteller's interpretation of the recounted events (Bell, 1988). Some storytellers present their evaluation as comments external to the story itself. Others may embed their evaluation of a story within any of the other elements of the story structure. Labov and Waletzky (1972) suggest that a variety of external and embedding strategies are consistently used to convey the interpretation of a recounted event. These include "direct statements", "lexical intensifiers", "suspension of the action using repetition", "symbolic actions", "judgements of a third person" (Labov & Waletzky, 1972, pp. 37-38), and "evaluative actions" tell[ing] what people did rather than what they said" (Labov, 1972, p. 373).

Resolution. The resolution clauses outline the outcome of the narrative clauses. As the conclusion of the story this element generally follows the evaluation statement(s).

Coda. The coda marks the end of the story. It is a device used by the narrator to

bring the storyteller and listener back to the present (Viney & Bousfield, 1991). When present the coda, like the abstract, assists in defining the boundary of the story. Labov and Waletzky (1972) suggest three linguistic mechanisms commonly used to accomplish this task. In some instances narrators "... use the linguistic category that points to a referent instead of naming it explicitly", such as "that, there, those" (p. 40) in contrast to the present tense of the story itself. In some situations the narrative is concluded by following one of the story participants into the present time. A third suggested alternative is accomplished by linking the effect of the storied events on the present situation. Labov (1972) also has suggested that

.... a good coda provides more than a mechanical solution for the sequencing problem: it leaves the listener with a feeling of satisfaction and completeness that matters have been rounded off and accounted for. (p. 366)

Generic and Kernel Stories

Although the unit of data analysis was initially first-person event-specific stories, other story genre including generic accounts, stories of usual behaviour, and kernel stories, stories-begun-but-not-told, were also identified in the interview data and included in the analysis process. As I examined the participants' interviews I quickly recognised that Labov and Waletzky's narrow definition of story that included only event-specific accounts was inadequate. As discussed previously, narratologists have suggested that narrative analysis must be concerned with not only the content of stories, the events of the first-person event-specific accounts, but also other story genre (Antaki, 1994; Langellier, 1989; Polanyi, 1985; Riessman, 1990a, 1990b, 1991). These researchers recognise that individuals communicate meaning in stories not only by manipulating specific story events but also by determining the structure

of the stories they tell. That is, individuals also communicate meaning by describing usual or habitual behaviour within a story form.

Strategies to Identify and Analyse Linked Story Meanings

Agar and Hobbs' (1982, 1983) narrative coherence paradigm was combined with Labov and Waletzky's model for the second level of the analysis process. Their work suggests a method for identifying recurring meanings between stories. This process involved what Bell (1988) calls the identification of "linked stories" within an interview and across interviews. More specifically, I conceptualised coherence or cohesion as described in Agar and Hobbs' (1982, 1983) work as the identification of recurring story "thoughts" (Ricoeur, 1981) or meaning in all the stories, first-person event-specific, generic, and kernel accounts within and across family-nurse unit interviews. Hence, in the analysis process meanings were first identified within each story and interview. Then, to determine and demonstrate coherence across interviews, I compared all meanings from individual family-nurse unit interviews, and subsequently all family-nurse unit interviews.

In addition, I adopted Riessman's (1993) understanding of story as representation in the analysis of both the content and meaning of each identified story genre. Therefore, I did not attempt to determine the congruence of the participants' recollection of events with the remembrances of other participants, but rather accepted their stories as fundamental meaning making structures.

Discourse in Stories

Finally, the discourse within the identified stories was also examined. This process

included an identification and analysis of the discursive and rhetorical devices used by participants in the telling of their stories about an acute exacerbation event. Initially, although I was able to identify the structure, content, and meaning of stories using the narrative analysis models, I was unable to clearly determine the constituents of a "good" story. It felt as though I had reached an impasse in the analysis process—that I was "eating soup with a fork". I therefore reread the descriptions of the application of these models by a number of social scientists. In many of the analysis reports the process of determining the goodness of an account was related, in part, to the discursive and rhetorical devices within the identified stories. As described above, I again recognised that Labov and Waletzky's work highlighted a number of discursive strategies commonly used in the evaluation segment of stories (Labov, 1972, 1982; Labov, & Fanshel, 1977; Labov, & Waletzky, 1972). It therefore seemed appropriate to look for the use of these devices in all elements of each story (Antaki, 1994; Bennett, 1986; Cowan, 1994; Polanyi, 1979, 1985).

From a review of this literature, it became apparent that individuals intentionally or subconsciously employ discursive and rhetorical strategies to clarify or strengthen the meaning they are communicating: i.e., metaphors, stylistic devices such as idea repetition; rhetorical strategies such as direct quotations and word and phrase repetition; and variations in the tone or form of presentation. Examination of these aspects of stories assisted in more adequately understanding the structure, meaning, and function of specific stories. This process also made explicit the elements that determined what strategies were used to effectively communicate meaning—what made a "good" story (Bennett, 1986).

In summary, I employed a broad definition of story as a limited genre for this

project. Stories as units of analysis were conceptualised as being both first-person event-specific, generic, and kernel stories. These various story genre were distinguished by their defining characteristics such as "...verb tense, temporality, sequencing, [and] discourse markers..." (Riessman, 1990, p. 1196). They were analysed in three sections of the interview data: as discrete first-person event-specific, generic and kernel stories within each interview; as linked meanings of stories identified within individual interviews; and as larger linked meanings that I located across the family-nurse unit interviews. The following section will describe the application of this analysis strategy leading to the development of discourse accounts of each meaning category.

Application of the Analysis Framework

The following steps outline the analysis process that I rigorously and methodically applied to each interview in the data base.

Description of interview context. A description of the interview context and patient admission data were developed for each family unit using the field notes and journal data created at the conclusion of each in-depth interview (Table 2, Appendix A). Information related to the patient's medical history obtained from the patient's hospital chart was also included in the family unit description: i.e., history of the patient's chronic pulmonary disease and prior admissions for acute exacerbation events. This information subsequently informed the interpretation of the stories.

Development of the interview data base. Each interview was transcribed completely. Notations were made on the transcriptions to indicate aspects of oral text such as pitch/loudness, pauses and non-lexical expressions, overlaps in speech, dialect,

and discourse markers (see Table 3, Appendix A for transcription conventions). An attempt was made to ensure that the text reflected the breathlessness of the patients, particularly when this difficulty interrupted the flow of the interview. The transcripts were not tidied. All the conversation which occurred during the interaction was incorporated into the transcript including speech interruptions, false starts, and overlaps in speaking turns. The phrasing was marked and each line of the transcribed text was sequentially numbered. Each interview was listened to a minimum of three times during the course of the transcription process.

Identification of stories throughout the data. First-person event-specific, generic, and kernel stories as the basic unit of analysis were identified in each interview (see Table 4, Appendix A). Each story was parsed according to structural elements as outlined by Labov and Waletzky (1972). Identification of both a complicating action or plot and some form of evaluation or interpretation clause was necessary for a section of text to be designated as a first-person event-specific or generic story. Kernel stories (Connelley & Clandinin, 1990; Kermode, 1981; Viney & Bousfield, 1991) were also identified within each interview. These sections of text consisted of abstract and evaluation clauses but lacked a complicating action element. When available, the impetus for the story, the stimulus, was also identified, particularly if the story was told in response to an interview question or statement (Labov & Waletzky, 1972). I also included my comments as interviewer to acknowledge the inter-subjectivity of story construction (Attanucci, 1991).

Identification of story events and story meanings. The events around which the stories were constructed and the meaning of each story was then identified (see Table 5, Table 6, Appendix A). Story events and meanings were compared across family-

nurse unit interviews in order to identify the common storied events and linked story meanings. The process resulted in the identification of common story events and linked story meanings (see Table 5, Table 6, Appendix A).

Presentation of content, structural components, and functions of stories by story meaning. This step involved the rereading and analysis of the content and structure of the parsed stories in each meaning category (near-death, vulnerability, causes of illness, and nurse template) across the data base. A discourse was developed for each meaning category presenting the common content, structural elements, and discursive strategies for each linked meaning so that they cogently supported the conclusions of the analysis. This discourse was informed by the context in which the stories were told.

Presentation of story segments. Excerpts from several stories from across the data base within each story group were included in each discourse presentation. These data segments were presented to provide analytic evidence to warrant the conclusions presented regarding the common structural elements and function of specific story meanings (Cowan, 1994). This presentation was informed by the context in which the stories were told.

Presentation of extended narrative segments. Longer segments of narrative texts as case examples of stories from individual interviews were presented at the conclusion of each chapter. Descriptions of the context in which the stories were told introduced the story segments. Complete stories were presented to illustrate the application of a Labovian framework in the identification of distinct story units (Labov, 1972) and to explicate my application of a narrative analysis framework in the development of each

linked story meaning. The extended narrative segments were also included to make the analysis process transparent and to facilitate the reader's audit of the described process of narrative inquiry.

The analytic strategy used in the study is presented in diagrammatic form in Figure 1 below. Although these steps are presented in a linear manner, this was not a linear process. Some steps were overlapping and often steps were revisited as the analysis process progressed.

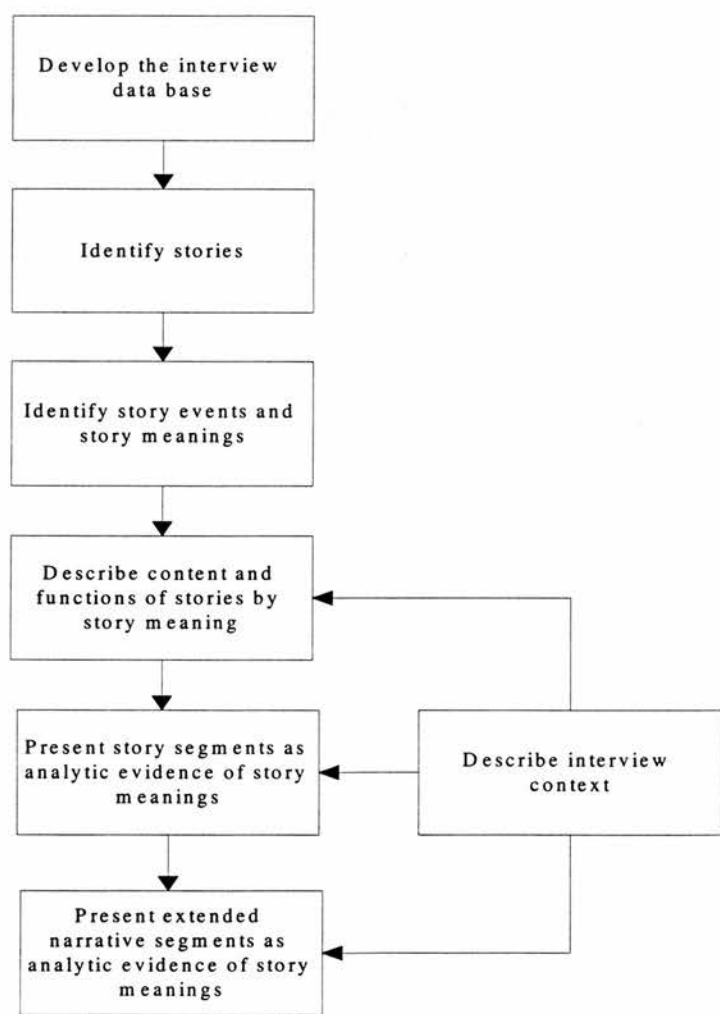


Figure 1: Framework for Narrative Analysis

Summary

In summary, the qualitative paradigm provides a method for understanding meaning within the context of the natural environment. In particular, the preceding discussion illustrates that the underlying assumptions of ethnography, an interpretive method that defines knowledge as an emic complex contextual construct of meaning, philosophically fit with my research aim to understand the meaning of acute exacerbation events from the perspective of patients, family caregivers, and nurses. Although the issue of goodness or quality within this natural paradigm continues to be problematic, my decision to use analysis of story as the way of handling the interview data, in part, was a strategy for maintaining the integrity of the stories as told by the study participants as they made sense of acute exacerbation events.

As indicated, an ever increasing number of studies reporting some association with narrative as an approach to either data collection or analysis have been reported in the nursing research literature. The cited studies demonstrate that narrative inquiry, as an extension of ethnographic research within the qualitative paradigm, provides a method for uncovering meanings that respects the context of in-depth interviews. These studies also illustrate the need to clearly identify and attend to a systematic approach of analysing stories within interview data. The analysis strategy presented for this study includes a blend of Labov and Waletzky's functional model, Agar and Hobbs' referential model, and attention to the discursive and rhetorical aspects of stories. The systematic steps outlined above reflect my concern for the maintenance of goodness in the uncovering of meaning.

CHAPTER 5

COPD ILLNESS STORIES

A preliminary review of the interview data revealed that the participants did indeed include stories when they talked of their experience of an acute exacerbation of chronic lung disease. It was therefore apparent that a form of interpretive analysis that respected the integrity of the limited genre stories used by these participants was an appropriate strategy for determining their understanding of this event. In the following chapter I will describe the study setting and participants, and outline the data gathering strategies used in this study. The chapter will conclude by introducing the analysis of the participants' interviews that are to follow.

Study Setting and Participants

The study was conducted in Canada, in two general hospitals in a Northeastern Ontario mining community of 160,000 people. These institutions were selected because they housed all the emergency admissions of individuals with acute exacerbations of chronic obstructive pulmonary disease in the region.

Ethical approval was obtained from Laurentian University, Sudbury General Hospital, and Sudbury Memorial Hospital (see Ethics Documents, Appendix B). As part of this review process a research protocol outlining data collection procedures was established. Over the four month period of data collection that followed ethical review (November 1, 1995-March 1, 1996), the admission clerks in the hospital emergency

departments notified me daily of the admission of individuals hospitalised with an acute exacerbation of COPD. I reviewed the charts of each potential patient participant within 24 hours of their admission to hospital to determine whether these individuals met the study inclusion criteria: i.e., had experienced at least two previous acute exacerbations of COPD necessitating hospitalisation, were currently hospitalised because of an acute exacerbation of COPD characterised by extreme dyspnea, and had named family members as the next of kin. Patients who met these criteria were approached and asked to be part of the study.

The study aim was explained to each identified patient. If they agreed to participate they were asked to name two family caregivers who were involved in their care during acute exacerbation events and who they thought might also take part in the study. Patients were asked to designate family members that had been involved in an acute exacerbation event and had a commitment to their wellbeing on an ongoing basis (Gilgun, Daly, & Handel, 1992; Johnson, 1998; Stuart, 1991). After obtaining the patient's informed consent (see Consent Forms, Appendix B), one nurse who was assigned to the patient's care on the in-patient unit was also asked to participate in the study.

A family-nurse unit was enrolled in the study if all identified individuals agreed to participate. At the request of the Sudbury General Hospital's Bioethics Committee, a letter was placed on the chart of patients participating in the study who were admitted to that facility. This letter, addressed to the patient's family physician, indicated that the patient and their family had consented to participate in the study (see Physician Letter, Appendix B). In order to ensure interview data suitable for qualitative analysis only English speaking family-nurse units were included in the

project. Families asked to collaborate were representative or typical of families who have a member with COPD (Chenitz & Swanson, 1985; Hammersley & Atkinson, 1989; Spradley, 1980). New family-nurse units were recruited into the project until thick descriptions of the acute exacerbation event were obtained.

Ten family-nurse units participated in the study interviews (see Table 2, Appendix A). Two additional family-nurse units were interviewed at the beginning of the study, but not included in the data analysis because of technical problems with the audio-taping. Seven of the patients were males, three were females. They ranged in age from 60 to 88 years of age, six were married, three were widowers and one a widow. Eight lived with their spouse or family while two men lived alone. In 6 of the 10 family-units the spouse was the primary caregiver while in four the primary caregiver was one of the patient's adult children. The second family caregiver was usually one of the patient's children. The families asked to collaborate in the study appeared to be representative or typical of families who have a member with COPD: i.e., they had been living with chronic lung disease for several years and had experienced at least two previous acute exacerbation events requiring emergency hospitalisation.

At the time of the study the two participating hospitals were in the midst of "down-sizing" (reducing the number of beds within their facilities because of budgetary constraints). One of the implications of this process was that patients, regardless of the admission diagnosis, were sent to any available bed in the hospital. As a result, five patients who participated were cared for on a nursing unit normally accustomed to looking after patients admitted with a primary diagnosis of an acute exacerbation of chronic lung disease. Of the remaining five patients, three were cared for on a cardiovascular investigational/surgery unit, one on a general surgery unit, and one on

a neurosurgical unit.

Data Collection

Part of the research purpose was to obtain a description of the decision making process used by individuals and families in seeking professional assistance during an acute exacerbation of their illness. I therefore initially approached patients within 24 hours of their admission to the in-patient unit. In consultation with the nurse caring for the patient, I determined when the patient was physically able to complete the interview. When well enough to talk, these patients were interviewed in the hospital, usually at the bedside. They were all receiving supplemental oxygen and intravenous steroid and antibiotic therapy.

Where possible family members were interviewed separately in their home (10 family caregivers). When this was not convenient for a family member, the interview was conducted while they were visiting in the hospital (6 family caregivers). Nurses were interviewed at their convenience during a break in their work shift. All interviews were tape recorded under conditions of informed consent. Socio-demographic and illness-related information was obtained from the hospitalised individual's medical records (see Table 2, Appendix A). This included data regarding the patient's past illness history, the nurses' and doctors' notes regarding the patient's admission and orders related to the present admission. Field notes were also written immediately following the interview sessions.

As indicated, for the purposes of this research, an acute exacerbation event of COPD was defined according to Strauss and colleagues' (1984) model of managing a medical crisis of a chronic illness. After introducing myself to the participants and

explaining the purpose of the study, open-ended, in-depth interviews were conducted with each participant. The interview questions were based on Strauss's model: "reading the signs", "organising for crisis", "breakdown of organisation: potential and actual" and "ceding responsibility to the hospital" (see Table 7, Appendix A). Each participant was initially asked to talk about the circumstances surrounding the patient's present acute exacerbation event.

At the completion of all the interviews, as outlined in the analysis protocol, the first stage of the analysis was to ask three questions of the transcribed interview data. The first question posed in the process of analysis asked how patients, family caregivers, and nurses talked about their experiences of an acute exacerbation of chronic lung disease. A second question asked what these individuals talked about as they made sense of extreme breathlessness necessitating emergency hospitalization. Finally, the data were examined to explore what the meaning of an acute exacerbation event for all three groups of participants. The meanings from each account were examined to determine how different groups of story meanings functioned in communicating the understandings of acute exacerbation events from the patients', family caregivers', and nurses' perspective.

Story Analysis

In answer to the initial analytical question, *how participants talked about an acute exacerbation event*, I discovered that patients, family caregivers, and nurses, in the context of the research interviews, communicated their understanding of these episodes, in large part, by telling stories of their experiences. Five hundred and three stories were identified throughout all participant interviews and conformed to the three

main story genre previously defined, first-person event-specific, generic, and kernel stories (see Table 4, Appendix A). Some differences were identified in the types and structures of stories told by patients, family caregivers, and nurses. These differences will be addressed in the subsequent chapters.

Story event categories. During the process of analysis, participants, often in response to the interview questions, talked of various aspects of acute exacerbation episodes. Each story was initially categorised according to story event using a typology that will be referred to throughout the following chapters. The four event categories were admission circumstances, nurse-patient interactions, causes of acute and chronic illness, and general circumstances of living with chronic lung disease characterised by acute exacerbation events (see Table 5, Appendix A).

Story groups. Two broad but distinct groups of stories were also identified: i.e., stories told by patients and family caregivers and stories told by nurses (Table 6, Appendix A). Patients' and family caregivers' groups of stories—groups of stories that I have labelled "linked" story meanings—essentially described an acute exacerbation episode as a crisis event and highlighted the causes of chronic and acute illness.

Patients and family caregivers understood an acute exacerbation event as a consequential and distressing component of living with this chronic illness. They talked not only of experiencing the continuous burden of an ever declining illness trajectory, but also described facing the additional challenge of managing frequent potentially life-threatening acute exacerbation episodes. Nurses, on the other hand, talked of acute exacerbation events within the context of the usual in-hospital care of patients who have chronic lung disease.

Linked story meanings. Three linked story meanings were identified in the patient

and family caregiver stories. A number of the patient and family caregiver stories described the events that preceded or precipitated emergency hospitalisation. These meaning categories included stories about the fear of death, perceptions of the patient's physical and emotional vulnerability, and causes of chronic and acute illness. Elements of Strauss and colleagues' (1984) conceptualisation of an acute exacerbation event as a medical crisis—"reading the signs that portend crisis", "organizing for crisis", and "ceding responsibility to the hospital"—could also be identified in many of their accounts.

Nurse stories were essentially accounts of their work and centered on the care of COPD patients on the in-hospital units. Nurses most frequently talked of the usual physical attributes and physical and emotional behaviours of patients admitted with an acute exacerbation of their chronic lung disease. Although their interviews included stories based on some of the same events as other participants (admission, causes of acute illness), the nurses' accounts did not reflect the drama of an unfolding emergency or medical crisis seen in the patients' and family caregivers' stories. Rather their stories highlighted their understanding of the usual relationship of anxiety and breathlessness as well as the normal nursing care provided by these nurses.

The broad story meanings, identified in both the patients', family caregivers', and the nurses' stories, in some measure, portrayed an acute exacerbation event as a metonymy of these participants' experience of living with COPD characterised by acute episodes of breathlessness requiring emergency hospitalisation (Selden, 1985; Lakoff & Johnson, 1980; van der Geest & Whyte, 1989). Although the initial interview questions focused on the events of the particular acute exacerbation event for which the patient was presently hospitalised, participants, patients, family

caregivers, and nurses alike, consistently talked of these events within the context of the patient's chronic illness. Their stories defined their understanding of an acute episode as a representation of the total experience of living with this chronic illness—what Lakoff and Johnson (1980) characterise as a "part for whole metonymy" (p. 39). The participants' understanding of the experience of an acute exacerbation event "[stood] for" their understanding of living with COPD (Lakoff & Johnson, 1980, p. 36).

In the following chapters I will examine the story meanings as told by patients, their family caregivers, and nurses illustrating the meanings of acute exacerbation events for these participants. Their stories will illustrate the function of acute exacerbation events in the context of living with this chronic illness for this group of participants.

Conjectural knowledge. Finally patients, family caregivers, and nurses included a kind of conjectural knowledge in their storytelling (Ginzburg, 1990). They spoke about signs or clues when talking of their experiences of acute exacerbation events. The following examination of these stories will therefore also demonstrate the use of these signs or clues by all participants. The discussion will illustrate, that, although there were some similarities in the signs or clues identified as markers of acute respiratory distress across all participant stories, differences did exist both within and between participant groups in both the clues talked about and the use of these signs by participants in the telling of their stories. Further, throughout the analysis of the two groups of stories, it will also be apparent that these signs were intricately tied to the stories and contexts in which they were told.

In Chapters 6, 7, and 8 I will examine the stories told by patients and family

caregivers. In Chapter 6 stories that included references to death will be explored. I will look at stories describing the patients' perceptions of physical and emotional vulnerability in the face of increasing breathlessness in Chapter 7. In Chapter 8 I will examine patients' and family caregivers' stories about the causes of their acute and chronic illness. In Chapter 9 I will examine the stories nurses recounted of their work with patients during hospitalisation for an acute exacerbation event. In all four chapters I will examine the structure, content, and function of the identified stories for the relevant information.

The intent of each chapter is to describe how these individuals represented their experiences of acute exacerbation events through storytelling. To facilitate the reader's understanding of the presentation of the data, I have outlined in each chapter the process I used to interpret the meaning of the participants' stories. This process includes the identification of story structures, content, and evaluation phrases specific to each linked meaning. I have particularly attempted to clearly delineate "the interface" of my interpretation structures with the meanings presented by the participant storytellers (Denzin, 1989, p. 54). Excerpts from several stories have been included in my descriptions, in part, to illustrate my analysis of the meanings of individual acute exacerbation events, and also, to introduce some of the complete participant accounts presented as example stories at the conclusion of each chapter (Riessman, 1990a).

Case examples at the conclusion of each of the following four chapters have been included to further illustrate the meanings presented by these participants in their talk of their experiences of acute exacerbation events, and to more completely explicate my application of a narrative analysis framework in the development of each linked story

meaning. The longer segments of narrative from participant interviews have been provided to make the analysis process transparent and hence facilitate the reader's audit of my systematic use of the described process of narrative inquiry. This presentation strategy is also intended to make explicit my interpretive journey (hermeneutic circle) and distinguish (as far as possible) my interpretation of meaning from the understandings and voices of the participants (Denzin, 1989; Riessman, 1993). Although the details of each family unit are unique, broad linked meanings were developed over the respective data sets: i.e., patients' and family caregivers' stories, meanings of near-death, vulnerability, and causes of illness; and nurses' template stories. The extended narrative segments are therefore presented as examples of the common elements of structure, content, and evaluation.

CHAPTER 6

DEATH STORIES

"I thought he was a goner /Was so bad"

Patients and family caregivers told a number of stories about death when describing an acute exacerbation of chronic lung disease necessitating an emergency admission to hospital. These death stories usually portrayed two kinds of acute dyspneic episodes. They described either a distinct moment in time when the participant thought they or the person they had been caring for had died (and been resuscitated), what I have called a near-death story; or an incident when the storyteller feared dying or witnessing a death event, what I have called a shadow-of-death story.

As I examined the death stories, I identified structure and content elements common to both near-death and shadow-of-death stories. For example, in most death stories the participant described the dyspnea they or the individual they were caring for experienced, the actions they had initiated to obtain professional help, and the eventual outcome of the acute dyspneic episode. I also observed that patients and family caregivers, in all death stories, talked of their fear—either fear of dying or of witnessing another near-death event.

It also became apparent that near-death stories usually represented a unequivocal change in the participants' understandings of an acute exacerbation event. That is, near-death acute exacerbation episodes functioned as watershed experiences in the patients' and their family caregivers' perception of the patient's chronic lung disease and their experience of intractable dyspnea requiring hospitalisation. They spoke of

the first near-death event as the beginning of their illness experience and now recognised that they would ultimately die during an acute exacerbation event.

Hence, individuals who had experienced a near-death acute exacerbation event subsequently lived in the shadow of that near-death experience. When these participants told stories of other acute dyspneic episodes, they frequently compared their present experience with the previous near-death event. In addition, their ensuing stories conveyed a sense of foreboding and fear, symbolising the shadow of uncertainty under which these individuals now lived.

In eight of the ten family unit interviews, patients and/or their family caregivers told death stories (see Table 6, Appendix A). In the next section I will consider the structure, content, and function of these death stories in more detail. The initial purpose of this discussion is to further explicate my understanding of near-death and shadow-of-death stories. This process is also intended to communicate how analysis of the structure and content of these death stories contributes to understandings of the meaning of acute exacerbation episodes of COPD necessitating emergency hospitalisation, from the patient's and family caregiver's perspective.

Death Stories: Structure and Content

As already suggested, two groups of death stories were identified in the participants' interviews. Story excerpts are initially presented as examples of these death story groups. They are excerpts from more complete story segments that will be examined in detail later in the chapter. One section of P4's interview, shown below, is an example of what I have characterised as a near-death story. This patient, a retired carpenter, talked of the circumstances of an acute exacerbation event when he believed

and family interviews will assist in illustrating the watershed and shadow function of these stories as near-death and shadow-of-death accounts.

The following excerpts will also show that a variety of rhetorical devices and discursive strategies were used by the participants in their stories to vividly communicate the dyspneic experience, help-seeking behaviour, and timely rescue. The most frequently employed approaches included the use of representations of "actual" conversations and word or phrase repetition. Some participants used metaphors, others increased the intensity and/or speed of their talk. Many patients and family caregivers, overcome with emotion, cried as, in telling their story, they relived the experience.

Intractable Dyspnea

Participants usually began their death stories by describing the circumstances of the patient's experience of intractable dyspnea. Invariably this section of the story was presented, in part, by the use of the first-person event-specific genre. Often the participants included those behaviours that the patient or their family caregiver used as their marker of an intractable dyspneic episode: for example, the loss of bowel control, the inability to speak, an increase in physical weakness, inability to sleep, changes in physical appearance, and choking. These behaviours were presented as evidence of the participant's interpretation of the seriousness of breathlessness episodes. The following excerpts from patients' and family caregivers' death stories characterise the intractable dyspnea experience as patient-specific and imprecise:

P5

22 P5: And that [hh] /let me see February /was March the first /yeah
23 March the first /some where around that...I found myself at home
24 that I couldn't hardly breath

P7
22 P7: But I come so bad /..I cannot go from the my bed /[h] back to
23 his chair /not portable toilet /[h] I **just** could not make it /I **just** lost
24 all energy

P7
126 P7: I choke /I saw my fingernail
127 **blue**
128 PAT: Umhum
129 P7: Purple an' /no **blue**

CG7.1
11 CG7.1: Be' before she went /ah at night she get up /s' she went to
12 washroom /den she **tried** t' /she was short of air /she went to the
13 kitchen /**tried** to get ahm ah medicine /puffs /an she **couldn't** do
14 nothing /she got not enough power /to reach that /an was only /ah
15 level with ah /with her hand /so she ah she **tried** and /it was ahm ah
16 /I have arthritis /an I **just** fall asleep before that happen /I **couldn't**
17 hear her bouncing around /so then quarter after four /at least a I
18 hear /ah she some kind of special noise /noise in the kitchen /I went
19 there /she was panic /she **couldn't** get no air /she **couldn't** get no
20 medicine /she **couldn't** wake me up

CG8.1
29 CG8.1: /he was **just** choking for breath /he was /he **just** couldn't get a
30 breath

P9
4 P9: Can't take my breath eh c' **couldn't** /..choking
5 PAT: ..Yeah
6 P9: Can' ah /..I **couldn't** breath you know

CG11.1
12 CG11.1: He ah...couldn't breath /ah like an you know normally /ah
13 /he's was up most of the night /and when he did breath /you could
14 hear all over /he was going [HH] [-h] /like this eh

P12
24 P12: /[h] dis time /Sunday [h] /I was **puffin 'n puffin 'n puffin** /[h] an
25 I knew there was something wrong /'n I was start to shake

CG12.1
47 CG12.1: Couldn't breed **at all at all at all** /well he [P12] breed like you
48 know but

CG12.1
8 CG12.2: I ah he went to the bathroom /and ah /he went to the
9 bathroom /and he he had he has a **hard time** /..[taps table] to get up
10 and walk /he has a really **hard time** /breathing /he can't **catch his**
11 **breath** /an den he has to sit in the bathroom ten minutes /an wait
12 until he gets his wind again /but he's so exhausted /dat he he **just** ah
13 /**how did he do it he goes** [h] [-h] [h] [-h] [h] [-h] /like he..
14 PAT: Umhum
15 CG12.2: He **just** can't seem to **catch his breath** /like he's not getting
16 enough oxygen

CG12.2

42 CG12.2: Ahm...[taps table] ah how did it go /he **just** ah....he **just**
43 /he **couldn't** ah be ah like we had /he was out of breath /he **just**
44 **couldn't** ah make it from the bathroom to the bedroom /and it's **just**
45 downstairs /there's no stairs or nothing /he **just** /sat down an he says
46 "I can't breath"

Many patients and family caregivers cried as they spoke of the details of acute exacerbation events. As indicated in the highlighted portions of the above examples, patients and family caregivers also used a number of rhetorical and discursive devices to vividly portray the patient's intractable dyspnea. For example, several participants repeated words or phrases to emphasise the severity of the dyspneic experience—"she tried", "she couldn't", "hard time", "puffin'n puffin 'puffin", "at all at all at all", "catch his breath". Family caregivers also often mimicked the breathing behaviour of the patient in order to vividly portray the patient's distress—"he was going [HH] [-h] /like this eh", "how did he do it he goes [h] [-h] [h] [-h] [h] [-h]".

Several participants also employed the particle "just" in their descriptions of the patient's behaviour to express an "emphatic" or "restrictive" meaning (Lee, 1987). In some stories just was used to emphasise the severity of the patient's dyspnea during a particular acute exacerbation event—"I just could not make it /I just lost all energy", "He was just choking for breath /he just couldn't get a breath". In other stories just was used in a restrictive sense. For example, in some accounts its use emphasised the experience of intractable dyspnea by highlighting the physical limitations that accompanied acute breathlessness—"and it's just downstairs /there's no stairs or nothing".

Help-seeking

In another element of the death stories participants usually described the actions

of both patients and family caregivers when they attempted to seek help to deal with what they believed was unmanageable breathlessness. Most participants told of experiences of dyspnea that happened outside of the hospital. In these situations they stated that normally the patient's initial action was to alert a spouse or an adult child of their increasing breathlessness. It was the family caregiver who then worried about the emergency transfer of their relative to the hospital. In some situations the family caregiver, familiar with the patient's normal behaviour, called for help upon recognising the signs of acute distress.

Individuals who lived alone reported essentially the same pattern of family-centred help-seeking behaviours. They too called one of their children who then hastily initiated the acquisition of professional help. Some families described a well established help-seeking protocol for the management of emergency transportation during acute exacerbation events. The following examples illustrate that these patients and families often delayed seeking help until they were convinced that they could no longer manage without outside assistance. The following excerpts from patients' and family caregivers' stories are examples of help-seeking behaviour. The highlighted segments demonstrate that patients and family caregivers frequently used direct quotations as one rhetorical device to vividly portray that the patient's acute distress necessitated seeking outside help:

P5

23	P5:	...I found myself at home
24	that I couldn't hardly breath	
25	PAT: Yeah	
26	P5: I aah...finally called my daughter /an I says " I gotta go to the	
27	hospital /I am breathing too shallow" ../so [swallows] she come over	
28	/we called the ambulance	

CG5.2

55 CG5.2: Oh OK /aah /yeah he called me /and he said um /"I've gotta
56 go in /'cause it's ti'-I've gotta 'n" /you know /he he often he waits until
57 he's ah /..ah he gets panicky

P7

25 P7: /[h] I try to stay home
26 longer I can /[h] [-h] and I come so bad /[h] if hear me from the
27 room /and I say "Call ambulance"

CG7.1

58 CG7.1: This time /..this time I was ah /I wake up /ah what was
59 /quarter after four /quarter-about quarter after four /an she was in
60 trouble little bit /but was wide awake little bit in trouble /but she try
61 to delay /to not go in hospital /she no like go in hospital /to stay
62 home /den ah I hear some kind of garglin' /..I got up /..and ah I say I
63 said /"You want ambulance?" /she says "Yeah"

P12

24 P12: /[h] dis time /Sunday [h] /I was puffin 'n puffin 'n puffin /[h] an
25 I knew there was something wrong /'n I was start to shake /[h] an
26 then ah my my wife /she phoned the /[h] fire department /[h]
27 dey called the helicopter

CG12.2

45 CG12.2: /he just /sat down an he says
46 "I can't breath" /so we called an ambulance

The Rescue

The narrative phrase portion of many death stories also included an account of the events that I have described as a timely rescue. Often in the near-death stories the patients and family caregivers characterised the outcome as a miraculous or fortuitous rescue. They described the care that the patient received from ambulance attendants in their own home, arriving at the emergency department at the last possible moment, being given some efficacious drug, or receiving mechanical assistance to breathe. In all death stories participants implied that the actions taken during the rescue by health care professionals included interventions which they were either unable to do for themselves or to provide for their family member:

P5

112 P5: [-h] The end of February /I think...March April /yeah that's right
113 /[h][--h] /if I'd of gone to bed that night /I'd never woke up the next
114 morning /because that'ss /I didn't do anything opposite /an that's
115 when I passed out /lucky /being rolled into the emergency room

CG5.2

85 CG5.2: /um...I guess CG5.1 told you /like he he died in
86 February /[taps table twice] you know like they did **the code** /the
87 whole nine yards /he was gone /and then they ah...put the re'put him
88 on a **respirator**²⁴ an /kind of you know brought 'im back or whatever

CG7.1

129 CG7.1: When go in hospital /they get her up right away on /ahm
130 put **oxygen** on /they know what is /what was wrong /yes they save
131 her life four times

CG8.2

116 CG8.2: /when he goes from /from here to the
117 hospital in an ambulance it's' /soon as they get here /he has his
118 **oxygen** on /the guys are quite competent /at calming him down /and
119 ah 'n it's hospital /into a bed /'n onto **the monitors an everything**

CG11.1

214 CG11.1: they ah /they start with hookin' him up with the ah
215 /ahm **oxygen** an ah /you know the /the re'--the **suction** an all that /an
216 then they /this time they /he got ah **intravenous right away** /an ah
217 /an they were putting ah /like his **medication** into that at the same
218 time /same as it is there right now //they hooked him up
219 immediately
220 PAT: Yeah]
221 CG11.1: An ah eh had **x-rays** /an **blood tests** /an heart a heart ah
222 [laughs] /ah what do you call that?
223 PAT: Cardiogram?
224 CG11.1: **Cardiogram** /he had that too /so

CG12.1

81 CG12.1: Dey dat we dey call we call dem /dat's de fire department
82 /but it's the first response
83 PAT: First response /ahuh
84 CG12.1: Like you know /**dey come right away** /dey won't..I say f'
85 didn't take more dan five minutes for dem to get here /and dey give
86 him de **oxygen** right away /den dey called de /**air ambulance** eh?

As highlighted in the above examples, the urgency of the rescue was strengthened, for example, by the evaluation phrases in which participants made specific reference to the timing of the rescue—"being rolled into the emergency room", "they save her

²⁴

Respirator is a term that is erroneously used as a synonym for a ventilator. A ventilator is "an apparatus designed to intermittently or continuously assist or control pulmonary ventilation" (O'Toole, 1997, p. 1723).

life four times", "right away". The inclusion of life-saving actions that were provided for the patient by emergency or hospital staff also reinforced the concept of being rescued. By naming specific interventions participants further communicated that this was help that could not be provided outside of the hospital environment—"the code", "the respirator", "oxygen", "monitors", "intravenous", "medications", "x-rays", and "blood tests".

Incomplete Stories

Not every death story, however, contained all three narrative elements. The inclusion and completeness of each element depended, in part, on the identity of the story teller and the death story genre of the account being told. Family caregivers generally recounted more comprehensive near-death and shadow-of-death stories than did the patients themselves. It seemed, for example, that patients, perhaps because of the severity of their respiratory failure during these events, were often too sick during a near-death event to remember the events immediately preceding hospitalisation. As a result their accounts of near-death episodes were sometimes incomplete in relation to the death story structure outlined above. Knowledge of the episode resided in others including family caregivers. In these circumstances patients sometimes reported being told about their near-death event by their doctor or family caregiver and then used this information when telling a story of their near-death experience. As the following two segments illustrate, such stories were sometimes more general in nature emphasising perhaps the details of the rescue circumstances:

P5

43 P5: /..so

44 [h] the'll-I can't tell you very much more /of what happened because

45 I was out

P7

38 P7: / [h] even they
39 bring me in the hospital /..I don't know when they took me blood
40 /an I don't know when the' [h] /put me here /you know /'n they took
41 me from here /'n up here

Death Stories: Meanings and Function

Before proceeding with a description of the functions of death-stories in the development of my understanding of an acute exacerbation event, it is perhaps necessary to clarify the distinctions and similarities that I observed in the content of near-death and shadow-of-death stories. As discussed above, both death story genres shared essentially the same structure. However, in near-death stories participants spoke of an incident of respiratory failure that required extraordinary intervention measures to prevent death. In these stories participants reported not only that the patient had required emergency hospital admission; but also that the patient had either been cared for in an intensive care unit and mechanically ventilated, or had required a prolonged hospitalisation.

In contrast, in shadow-of-death stories participants told of episodes of less severe dyspnea requiring emergency hospitalisation or described how incidents of increased breathlessness were managed by hospital personnel before more intensive interventions such as mechanical ventilation²⁵ became necessary. Consequently, although shadow-of-death stories involved descriptions of severe shortness of breath and emergency hospital admission, they did not include accounts of complete respiratory failure and rescue from virtual death. A review of each patient's medical records verified that eight of these patients had indeed, on at least one occasion, been hospitalised in an

²⁵ Mechanical ventilation refers to the process of assisting or supporting a patient's breathing as a result of respiratory failure (O'Toole, 1997; Smeltzer, & Bare, 1996).

intensive care unit because of respiratory failure.

The following excerpts from near-death stories describe examples of intensive care admissions and extended hospital stays. They also demonstrate that the patients' and family caregivers' stories of these near-death events frequently included death information provided to them by their family caregivers or health care professionals. The inclusion of direct quotations, word and phrase repetition, and explicit details portrayed these events as serious and frightening experiences:

P4

333 P4: /[-h] **tree** [h] [pounds table] **times** in the [pound
334 table] same day code blue²⁶ [pounds table] /[-h] an I shit /my son's
335 here with me /he said [-h] "**you shit ALL over the place** /[-h] an die"

P5

47 P5: I woke up **six days** later /in ICU /at the [*specific hospital*] /...an
48 apparently the next m'-that night /they called my family in /'cause
49 they figured I'd had it /...the next morning /..I took ah /respiratory
50 failure /..an that's how I ended up in..ICU at the [*specific hospital*] /I
51 stayed in the hospital **two months**

P5

383 P5: /I woke up
384 PAT: Yeah
385 P5: An there's these little **pumps** all over
386 PAT: Yeah
387 P5: There was **pipes** in my neck
388 PAT: Yeah
389 P5: **Tubes** in my neck /tubes in my a' arm /..an ah..oxygen mask
390 with a lot of water goin' with it

P7

203 P7: The time I was in the hospital /[h] I was **one week** up here /then
204 after [h] [-h] ..I go back /....I manage I go **five weeks** that I don't
205 come out /....yeah /an' after it was **five weeks** /[h] an' they clean out
206 so much /oh my god /[h] hardly to believe

P10

191 in 1989 [h] I landed in the hospital here /for **45 days**
192 PAT: Um //short of breath?
193 P10: An I'm telling you] /I had ah bitch of a time
194 PAT: Yeah
195 P10: **Forty-five days** /I didn't know who I was /I didn't [h] know
196 where I was /[h] I didn't know what was goin' on /the doctors
197 would tell me something /I didn't know who he was /[h] it it's
198 unreal

²⁶ Code blue is a term used by hospital staff to indicate the sudden cessation of heart and lung function necessitating immediate cardiopulmonary resuscitation (O'Toole, 1997).

CG11.1

236 CG11.1: one one time he
237 come in /an he was in here **three or four days** /and he ended up in
238 ICU //it got so bad
239 PAT: Really]
240 CG11.1: He couldn't breath any more they /they had to put him the
241 respiratory /there for ah /what it was **three four days** he was on that

CG12.1

15 CG12.1: /den in November dey kept him for
16 **seventeen days**

Watershed Function

Given the similarity in structure and content of these two types of death story genre, it became apparent that both near-death and shadow-of-death stories served a particular function in the interpretation of acute dyspneic events. As already indicated, participants frequently spoke of these experiences in relation to one another. The presentation of a near-death event in comparison to a less serious episode of dyspnea suggests that the near-death event signified a change in the participant's understanding of acute exacerbations of COPD. In part, the near-death event acted as a boundary or watershed between the patient's previous level of health, present experience of chronic illness and ultimate death.

For some patients and family caregivers the near-death episode described in their stories appears to have been the moment that marked the beginning of their career as a family living with an individual with potentially fatal chronic lung disease. Indeed, one common characteristic of near-death (watershed) acute exacerbation events was that they often seemed to take patients and family caregivers by surprise. Though the patient's chronic lung disease was of long standing, the telling of a specific death story implied that until the near-death event, the seriousness of a gradually decreasing respiratory function was not particularly concerning to either the patient and/or their

family caregivers. The patients in these family units indicated having experienced, up until this point in time, only the usual non-acute symptoms of beginning chronic obstructive pulmonary disease: i.e., shortness of breath with exertion and increasing episodes of respiratory infections.

A story told by P10 is an example of this change in perception. In the following story, although P10 was aware of his lung disease for at least six years, the acute exacerbation event that required prolonged hospitalisation in 1989 (a near-death event) marked an important change in his understanding of his disease:

P10

- 189 P10: This started in 1982 /an kept gettin' worse /an worse /an every
190 year /my wife died in 1988 /I started gettin' really sick in 1989 /..an
191 in 1989 [h] I landed in the hospital here /for 45 days
192 PAT: Um //short of breath?
193 P10: An I'm telling you] /I had ah bitch of a time
194 PAT: Yeah
195 P10: Forty-five days /I didn't know who I was /I didn't [h] know
196 where I was /[h] I didn't know what was goin' on /the doctors
197 would tell me something /I didn't know who he was /[h] it it's
198 unreal
199 PAT: Yeah

As illustrated by P10's story, the acute exacerbation episode resulting in a near-death event was not only a new experience for the patient and the family caregivers, but a life-and-death experience, and, as such, functioned as a watershed event. This near-death event—"I didn't know who I was"—marked the boundary between the "before" and "after" life of these family units in relation to their knowledge and understanding of acute exacerbations of the patient's chronic lung disease. Hence, when participants were asked about their present experience of an acute episode of dyspnea they frequently talked about their present admission by situating it in relation to their previous near-death experience.

The following short evaluation excerpt from CG12.1's description of the circumstances surrounding her husband's present hospitalisation is another example

of what I have called the watershed function of near-death stories. In a shadow-of-death story this family caregiver talks about a current dyspneic event by comparing this admission to a previous and more serious dyspneic or near-death episode:

CG12.1

11 CG12.1: Well this dis time wasn't as bad as in November
12 /November I tought he /he was gone

In some family units a near-death acute exacerbation episode occurred after previous hospitalisations for unusually difficult-to-manage dyspnea. The near-death event in these stories, nevertheless, again represented a shift in the participants' understanding of the potential severity of what was previously (somewhat) bothersome but less severe shortness of breath. This was the group of respondents, for example, as shown below, who now talked of the establishment of clearly outlined strategies to ensure that the patient was taken to the hospital on time:

CG5.1

591 CG5.1: /so it's'a it's a
592 whole different...pattern now than what it was even five years
593 ago /because it's become such a /such'like we do all do it by rote
594 now /you know /...everything that has to be done

Indeed, their telling of the near-death story in the interview often conveyed the adjustment in the participant's expectation of the potential outcome of any future dyspneic event.

Shadow Function

As suggested above, the shadow-of-death stories told by patients and family caregivers frequently described the circumstances surrounding acute exacerbation events that, like near-death events, also required emergency hospitalisation. Although these death stories did not end in complete respiratory failure, their telling did reflect the patient's and family caregiver's experience of a previous near-death event. In the

shadow-of-death stories the participants told of deciding to seek help on this occasion not only because of the distress of increasing dyspnea, but also because they had experienced a near-death event.

The evaluation phrases included in shadow-of-death stories, like those in the near-death accounts, consistently referred to the possibility of death. This reiteration of meaning identified across stories also clearly reflected the influence or shadow of near-death experiences on the patients' and family caregivers' interpretation of any subsequent, even less serious, dyspneic episodes. The following two shadow-of-death stories provide examples of the relationship between the two types of death accounts, and hence, of this shadow experience. These family caregivers begin their description of an acute exacerbation event with a direct reference to their family member's prior near-death experience:

CG12.1

11 CG12.1: Well this dis time wasn't as bad as in November
12 /November I tought he /he was gone
13 PAT: Really
14 CG12.1: Yes /he was really bad

CG7.1

63 CG7.1: /but this
64 was not so-was bad /but not so bad as /once before /once before it
65 was terrible

Further, the telling of near-death and shadow-of-death stories within the same interview suggested that these individuals lived in the shadow of fear and uncertainty cast by their near-death experience. These patients and family caregivers consistently evaluated what I have defined as near-death and shadow-of-death experiences by saying that they were afraid either of dying during a future acute episode of breathlessness, or of watching helplessly as the individual they cared for became increasingly breathless and died before receiving emergency care. The following

excerpts are examples of evaluation phrases from patient and family caregiver near-death and shadow-of-death stories. The highlighted phrases again demonstrate the patients' and family caregivers' use of a variety of rhetorical devices such as word and phrase repetition and direct quotations to reinforce their overwhelming sense of fear and uncertainty—"he's afraid", "I'm gonna die", "it's a nightmare", "I panic":

CG5.1

351 CG5.1: /oh I mean I know when he's
 352 **afraid** just by...ah.../we've joke about this /the F word /you know /I mean he
 353 **NEVER** ah you know uttered a swear when we were kids /or growing
 354 up /and it's when he gets excited /an when **he gets afraid** /an then he
 355 swear a blue streak /at us /an at nurses /an at you know
 356 PAT: Yeah
 357 CG5.1: An yeah **he's afraid**

CG5.1:

574 CG5.1: We got into this routine OK /because initially I think that um
 575 /those were his feelings
 576 PAT: What?
 577 CG5.1: That a' that a I wa' /when I go to the hospital /"**I'm gonna die**"
 578 /like "**This is it**"

CG5.2

93 CG5.2: No he does not want that [*mechanical ventilation*] done again /**it's a nightmare for us**
 94 **too**

P7

131 P7: I think I die you know

CG7.1

50 CG7.1: /that the biggest problem /if you get panic an that thing
 51 /you can **no** get **no** air /you **no** get help /you can **no** even **puff** /**puff**
 52 /take **puff** in /that's ah affect /you got **no** help /just go in hospital /if
 53 you come in the right time /and ahm /they come in the hospital "**Five**
 54 **more minutes** /you be gone"

CG7.1

172 CG7.1: /....but that time says /doctor say "**Only five minutes**
 173 **more** /**be choke**" /[big breath] oh yeah lots of problem with that
 174 thing

CG9.1

206 CG9.1: So she [*caregiver's nurse-daughter*] says
 "You'd better prepare yourself for it" /said "**It's**
 207 **comin'** /she's not getting any better /she going down hill right now"

CG9.2

148 CG9.2: /you
 149 just say /"**Oh no**" /"**Here we go again**" /"**How long is--will this be**"
 150 /ahwah you know /ah "**Will she make it this time?**" /or ah "**How bad**
 151 **is this?**"

P10

213 P10: Yeah /my breathing's gettin' worse /**[h]** **I can't see /I can't see**
214 where I'm gaining **[h]** **[-h]** [coughs]

CG10.2

619 CG10.2: ...like the last..six months
620 over there /you could see that it was getting harder on him /now
621 that I'm gone /I not gonna see it but /I know it's not gonna look
622 **good** for him /like it's not gonna be **good** for him now /'cause I
623 know he ah gonna go down hill even more

P11

19 P11: and it's **very** scary /or if you can't get your breath /an it's thirty miles
20 to ah **[h]** the emergency hospital **//[h][--h]** **[h]** **[--h]** **[h]** **[--h]**

P12

73 P12: **[h]** Well the **second** ti' the **second** time /I thought I was gonna
74 die **[h]**

CG12.1

18 CG12.2: And then sometimes /we don't know if we're doing the
19 right thing by calling an ambulance or not /but we figured that he
20 needs oxygen /so dat's why we /an we get **scared** too /because I don't
21 want my dad **dying** of a heart attack /or...**die--**

CG12.2

168 CG12.2: **I panic** /I don't know what to make of it /I'm scared he's
169 gonna have a heart attack

Two longer segments of narrative text are now presented as examples of death stories told by patients and family caregivers. Like other participants in the study, both storytellers told near-death and shadow-of-death stories and described their understanding of an acute breathless episode as an experience dominated by a sense of uncertainty and a fear of death. Their accounts are presented to illustrate the application of a Labovian framework in the identification of distinct story units (Labov, 1972), to demonstrate the identification and use of death stories, and to explicate the analytical utility of these death story structures in interpreting the participant's understanding of an acute exacerbation event. P4, a retired widower, told death stories that described two acute exacerbation events that took place while he was a patient in the hospital. CG12.1, a wife and family caregiver, recounted death stories about the events of acute exacerbation episodes that precipitated her husband's

emergency admission to hospital. These extended narrative segments are examples of the structure, content, and meaning identified in death stories of acute dyspneic events across the data base.

Case Example #1

Mr. P4 was a 60 year old widower: a short and stocky retired carpenter who spoke with a heavy French Canadian accent. He had the characteristic barrelled chest of a life-long smoker and end-stage lung disease patient. He had difficulty completing any sentence without obvious breathlessness. His hospital records indicated a long history of COPD necessitating several emergency hospital admissions. He lived alone in a one bedroom apartment and identified his son as the one family member who helped him manage his acute episodes of respiratory distress. During incidents of intractable shortness of breath this son drove his father to the hospital.

Prior to this admission P4 had gone in turn to a community medical clinic, the emergency room of an acute care hospital, and his family doctor, complaining of increasing shortness of breath. The clinic physician, according to P4, diagnosed a possible lung infection, prescribed an oral antibiotic and sent P4 home with instructions that should his condition worsen he might require hospitalisation. After a self-initiated visit to a hospital emergency room the following day, P4 was again told to go home, take his antibiotics and see his family physician in a couple of days. During a visit to his family physician the next day P4 was once more sent home to care for himself. He finally gained access to in-hospital care by directly phoning the office of the respiratory consultant who had looked after him during a previous admission to an intensive care unit. According to P4, he was then immediately admitted to hospital with a medical diagnosis of acute exacerbation of COPD.

I met P4 on the in-patient unit the day after his admission. He was receiving intravenous steroid and antibiotic therapy as well as a combination of inhaled

bronchodilators²⁷ and cardiac medication. The research interview took place at his bedside. During the course of the interview he told a number of event-specific and generic stories, including six death stories.

The following is the full text of the first of two of the death stories told by P4. Both were told near the conclusion of the interview and describe separate episodes of acute breathlessness. They are presented using Labov's (1972) structural categories and method of transcription. I have attempted to capture P4's French Canadian dialect in the written text in a conscious effort to "... reveal [rather than] conceal aspects of meaning and intent" as presented by this participant's talk (Gee et al., 1992, p. 240). The discussion will illustrate the utility of interpreting these stories as near-death and/or shadow-of-death stories in the process of developing a more adequate understanding of how P4 understands an acute exacerbation of COPD.

P4: Shadow-of-Death Story

An' ...she said "OK /You can have a mask²⁸ an one pills"

Orientation:

291 Last spring/I go der an he he [*the doctor*] wants me [-h] to watch that ah
 292 heart check /check up [-h]
 293 PAT: Yeah
 294 P4: An he said for dat check up you can't take [-h] medication for
 295 your asthma /[-h] He said [h] for coup' two or three days maybe /[-h] OK

Complicating Action:

296 [-h] An at tree o'clock in the morning [-h] /I woke up
 297 Pat: Yeah
 298 P4: An I can't breathe [-h] /I said "Nurse give me someting an fast..
 299 [-h] I can't make it I can't make it" /[-h] "Mr. P4" [pounds table]
 300 "You [pounds table] can't do have nothing /You gotta test [pound
 301 table] tomorrow and you can't [pounds table] /An go to bed an relax" [-
 302 h]
 303 PAT: Re//lax?
 304 P4: "LISTEN" /LISTEN to [pounds table] me /I'm not gonna be here
 305 for that test /I'm gonna be [pounds table] die /I'm all-die right away
 306 /[-h] My eyes gone /[-h] an I shit all my pants /[-h] Ann. [-h]. I'm

²⁷ Bronchodilators refers to agents that relax the bronchial smooth muscle thereby dilating the air passages of the lungs (McKenry & Salerno, 1998).

²⁸ "Mask" refers to the administration of drugs by means of a nebulizer (McKenry & Salerno, 1998; O'Toole, 1997).

307 gone /I'm gone" /"We can't do /You got a test" [pounds table] /"Hey come
 308 on" /"[-h] You got a test" /"Come on" /[-h] Now I start to swear /[--h]
 309 You know can't
 310 PAT: Oh
 Evaluation:
 311 P4: Can't stand
 Complicating Action:
 311 /[-h] An my daughters coming /An she look my
 312 daughter /[-h] She said "I might [-h] -I'm gonna go call the doctor"
 313 [h] /An she call the doctor slow
 314 PAT: Your daughter or the nurse?
 315 P4: D'my dau' no the nurse
 316 PAT: Yeah
 Resolution:
 317 P4: [-h] An' ..she said "OK /You can have a mask an one pills"
 Evaluation:
 317 /[-h] An I
 318 just made it [-h] [h] /[pounds table] Hey that's that's-Don't know how
 319 you can trust /[-h] [-h] You can't trust /..AIR that's AIR /That's not ah
 320 finger cut /[-h] That's AIR /Your your heart need AIR [pounds table]
 321 /Ha ha ha ha [-h]
 Coda:
 322 PAT: It's an incredible story

This complete story describes a specific episode of dyspnea experienced by P4 during a previous hospitalisation. As storyteller, P4 clearly outlines the context of the storied events he is about to tell. About a year ago he was electively hospitalised for a cardiac assessment. During that hospitalisation, perhaps because of the withdrawal of his usual respiratory medication, he awoke with an acute episode of breathlessness. Having set the scene for his story P4 then uses the subsequent narrative phrases to tell a death story centred on an interaction between himself and a nurse caregiver. Although P4 spoke almost in a whisper, he vivified his story of this specific episode by dramatising the telling, raising his voice, pounding the over-bed table, and alternating between his own voice and that of the nurse caregiver.

The three structural components of a death story as previously outlined were also clearly identifiable in P4's account. P4 included a description of intractable dyspnea or shortness of breath:

296 [-h] An at tree o'clock in the morning [-h] /I woke up
 297 Pat: Yeah
 298 P4: An I can't breathe [-h]

Through the use of specific explicit details P4's other narrative statements portray his interpretation of the seriousness of his nocturnal breathlessness. He implies that his difficulty in breathing led to visual impairment, bowel incontinence, and, most importantly, a sense of impending doom:

304 P4: "LISTEN] /LISTEN to [pounds table] me /I'm not gonna be here
 305 for that test /I'm gonna be [pounds table] die /I'm all-die right away
 306 /[-h] My eyes gone /[-h] an I shit all my pants /[-h] ann. [-h]. I'm
 307 gone /I'm gone"

P4 then initiated his own help-seeking action by calling the nurse. His inclusion of direct quotations implies that the story is a presentation of the events as they actually occurred:

298 P4 /I said "Nurse give me someting an fast..
 299 [-h] I can't make it I can't make it"

Finally, a somewhat delayed rescue, was also described. After P4's protracted requests for assistance the nurse, albeit reluctantly, responds with what I have called a "timely rescue":

317 P4: [-h] An' ..she said "OK /You can have a mask an one pills" /[-h] An I
 318 just made it [-h] [h]

This story communicates, in part, P4's interpretation of the meaning of an acute breathless episode. P4's statements in the resolution section of the story imply that, from his perspective, he could have died had the nurse not appropriately intervened—"An I just made it". I have therefore interpreted the account told by P4 as a death story.

However, the nursing interventions as described are not congruent with a near-death event. The administration of a pill and one inhalation therapy would have been inadequate treatment for intractable dyspnea. Furthermore, the evaluation phrases that

follow the heart of the story clearly state that P4's purpose in telling the story was not primarily to highlight a near-death escape. Rather, P4's point in telling a story using death-talk was, in his words—"don't know how you can trust", to communicate something important about his sense of safety during an acute exacerbation event. P4's story structure and use of language exposed his fear of dying. It suggests that P4 lives in fear, what I have called the shadow-of-death:

P4's use of the above shadow-of-death story of an interaction he had with a nurse during an episode of acute breathlessness suggests that he believes that an acute exacerbation event is potentially life-threatening. Although the nurse's response minimises the severity of the dyspneic event, P4's telling implies prior experiences of acute unmanageable breathlessness. Indeed, P4 continues the interaction with another death story, an account I have categorised as a near-death story. The two stories are clearly linked:

Abstract/Generic Story:

Orientation:

Complicating Action:

Resolution:

335 /[-h] an die"

336 Hum

337 PAT: Yeah

Evaluation:

338 P4: I got a same ting in that night /[-h] "You gotta wait your test

339 tomorrow "[--h] [pounds table] [h] Phew /Em that's awful eh

340 PAT: Yeah ye//ah

341 P4: But] then i'y' it'y it's //awful

This second account, also a complete story, describes another specific episode of dyspnea experienced by P4 during an earlier hospitalisation. Unlike the first story, this second death story is introduced by a compelling metaphor in which P4 draws a parallel between the death experience of animals and people: vivid imagery presumably from his experiences as a farmer and hunter.

328 P4: /An [-h].. I'm ah hunter /[-h]

329 I'm farmer /[-h] I' no matter wh' how-what you want an' where I

330 got it /[-h] When you kill 'nother animal /[-h] it shit ha ha ha ha

This account, however, does not include all the structural elements of a death story. Rather, only a portion of one segment of the previously outlined death story structure, the consequences of the intractable dyspnea—bowel incontinence and then death—can be identified. The structural elements of help-seeking behaviour and timely rescue are not present. The incompleteness of the account suggests that P4, because of the severity of his respiratory failure had little or no memory of the circumstances surrounding his extreme dyspnea during the earlier episode. Notwithstanding these gaps, P4 tells an event-specific story, and dramatises the narrative events by employing the voice of his son as witness to his respiratory arrests—death:

333 P4 /[-h] Tree [h] [pounds table] times in the [pound

334 table] same day code blue [pounds table] /[-h] An I shit /My son's

335 here with me /He said [-h] "You shit ALL over the place /[-h] an die"

Although the story as a death account is incomplete, the intractable dyspnea resulting in complete respiratory failure and the implied timely rescue clearly

constitute a near-death event. P4 links the two death stories together by repeating his reference to bowel incontinence—"I shit"—a marker or signifier of potentially intractable dyspnea first experienced during this near-death event. His repetition of the phrase "same ting" also suggests his comparison of this acute event and presumably all subsequent dyspneic episodes with this near-death experience:

338 P4: I got a same ting in that night /[-h] "You gotta wait your test
339 tomorrow "

Again, for this participant, the evaluation phrases that follow the event portion of the story indicate to the listener that the point of reconstructing this singular moment in time was not only to inform the listener of the near-death experience, but also to once more portray his concern with personal safety—his fear of dying during a subsequent episode of breathlessness. In the telling of this near-death story P4 refers to the previous shadow-of-death account. Both the story event—near-death—and the obvious linking of the two stories portray this patient's understanding of acute exacerbation events as a situation in which he is afraid of dying.

The next case example includes extended narrative segments from a family caregiver's interview. Although the circumstances of the acute exacerbation events and the family structure are not the same, this participant also tells of her experiences of her husband's acute intractable dyspnea using death-talk stories, describing them as episodes of fear.

Case Example #2

P12, a 74 year old retired miner, was admitted to hospital complaining of acute respiratory distress. He lived with his wife, daughter, and eight year old multi-handicapped granddaughter. P12, a smoker until two and a half years ago when his lung disease became more bothersome, had a previous history of asbestosis, emphysema and hypertension. His chronic lung disease had left him with a barrel chest and the need to use his shoulder and neck muscles to breathe even at rest. P12 designated his wife, CG12.1, as his primary family caregiver. She shared this responsibility with her daughter, CG12.2, who at the time of the interview had lived with her mother and father for approximately four months. This daughter looked after her parent's financial matters and assisted in the care of her chronically ill father.

According to CG12.1, her husband had been hospitalised three times in the previous four months for acute exacerbations of his chronic lung disease. Each admission had involved the need for emergency care in the home, and, because of the distance of P12's home from in-patient care, had also meant an emergency trip to the hospital involving both land and air ambulance transportation. Because of the wintry weather CG12.1 had been unable to visit her husband regularly during this hospitalisation. However, she was eager to talk with me about her understanding of her husband's illness. I therefore interviewed her in her own home, a small wood frame house in a French Canadian village 30 miles north of Sudbury. During the course of the interview she told three death stories.

The following is the full text of these death stories. The first event-specific story describes the circumstances of P12's present admission. The following two stories describe the circumstances surrounding a previous acute exacerbation event; what

CG12.1 calls "De bad one" and what I have categorised as a near-death event. Again, the stories are presented using Labov's (1972) framework of narrative analysis, and demonstrate the communication of meaning by this family caregiver through the use of death stories. In addition, the utility of interpreting these caregiver accounts as shadow-of-death or near-death stories in understanding something of how CG12.1 understood an acute exacerbation of her husband's severe episodes of breathlessness will be described. I have again attempted to represent this participant's French Canadian dialect in the written text.

CG12.1: Shadow-of-Death Story

Well this dis time wasn't as bad as in November

Story Stimulus:

9 PAT: What we'll focus on initially at least is ah /What happened this
10 time /that had--have to go to the hospital?

Abstract/Evaluation:

11 CG12.1: Well this dis time wasn't as bad as in November

12 /November I tought he /he was gone

13 PAT: Really

14 CG12.1: Yes /He was really bad

Orientation:

14 /De first time happened October

15 /dey kept him for tree days /Den in November dey kept him for

16 seventeen days /And dey still said he didn't need the oxygen

Evaluation:

16 /But dis

17 time we didn't wait 'til he turned too bad

Complicating Action:

17 /We call right away for ah

18 /de first response here in our town

Evaluation:

18 /Dey're very good

Complicating Action:

18 /Dey give up all

19 de /like you know de //attention dat you needed

20 PAT: Yeah

Resolution:

21 CG12.1: Dey rush him in de hospital

Coda:

22 PAT: But what happened leading up to it?

I have classified this first section of CG12.1's interview as a shadow-of-death story. Although only two of the three structural elements of a death story can be identified in the above account, CG12.1's statements about help-seeking, calling the

"first response" team, and her description of a subsequent rescue clearly imply that her husband, prior to his hospital admission, had experienced an episode of intractable dyspnea:

17 /We call right away for ah
18 /de first response here in our town /Dey're very good /Dey give up all
19 de /like you know de //attention dat you needed
20 PAT: Yeah]
21 CG12.1: Dey rush him in de hospital

The above phrases indicate that CG12.1 was intimately involved in the events of this present admission. However, her story lacks not only information about her husband's dyspneic experience and details regarding the decision taken by the family to seek professional assistance, but also information regarding the implied complexities of the ensuing air ambulance rescue.

Instead of information about this present admission, the abstract and initial evaluation phrases provide specific details about another acute exacerbation event: introductory clauses that situate the present story within the context of this earlier, obviously frightening, experience. In the abstract section of the story, for example, CG12.1 implies that prior to this admission she had lived through a much more serious breathless episode. She states that during this previous experience her husband was "really bad"; so bad that she thought he had died—"he was gone":

11 CG12.1: Well this dis time wasn't as bad as in November
12 /November I tought he /he was gone
13 PAT: Really
14 CG12.1: Yes /He was really bad

The orientation phrases that follow also focus on this prior acute event. They contain additional details that differentiate this previous "very bad" experience from the present less serious—"bad"—episode. CG12.1 implies that one factor marking the earlier experience as "very bad" was the patient's prolonged hospitalisation:

Complicating Action:

46 PAT: Couldn't breathe?
47 CG12.1: Couldn't breed at all at all at all /Well he breed like you
48 know but /he he was /I don't know /He ah de first's one came /Dey
49 give him de oxygen /Den he said he felt better /so dey left /Dey
50 weren't gone at de corner /so we called dem right back /Den it was
51 /Like you know /Den dey rush him to de hospital /Thru de like you
52 know /Dey thru de air ambulance an

Resolution:

52 /He was dere seventeen days
53 dat time

This first episode of two near-death stories describing the circumstances surrounding a previous acute exacerbation event was initiated by a question that followed up CG12.1's earlier comparison of her husband's present admission with a previous apparently more serious acute exacerbation event. In the abstract, which also performs an evaluative function, CG12.1 again compares the current admission with another acute event. She reiterates that the present acute episode was less serious—"not quite as bad"—as the "November" experience:

39 PAT: So ahm now /how did you compare this one to the previous
40 one?
41 CG12.1: Dis one not--was not quite as bad as /de one in November
42 PAT: What happened then?

The narrative phrases of the story describe the "November" acute exacerbation event. All three structural components of a death story—intractable dyspnea, help-seeking behaviour and a timely rescue—can be identified in this account. However, in contrast to the previous shadow-of-death story about the present admission, CG12.1 provides explicit details about her husband's intractable breathlessness. Her repetition of the phrase "at all" poignantly portrays a picture of acute respiratory distress that was both terrifying and beyond CG12.1's ability to manage as a family caregiver:

47 CG12.1: Couldn't breed at all at all at all /Well he breed like you
48 know but /he he was /I don't know

The phrases that describe this particular experience of help-seeking behaviour reflect a sense of the uncertainty experienced by family caregivers and professional

43 CG12.1 /An I
 44 tought he was he was goner /I tought he was a goner /Was so bad
 45 /It scared de daylights out of us

Moreover, in the above evaluation phrases CG12.1 implies that the point of this story was not only to compare this present admission with the "November" episode, but also to communicate the watershed nature of this previous terrifying experience. For this family caregiver this near-death event appeared to marked a unequivocal change in her understanding of her husband's chronic lung disease. She now compared subsequent dyspneic events with this experience. In a second telling of this near-death story CG12.1 again portrays the unique watershed nature of this near-death event for herself and her family's understanding of subsequent acute exacerbation events.

CG12.1: Near-Death Story Episode 2

De first time /De bad one dere /We couldn't see it coming

Story Stimulus:

68 PAT: Yeah yeah /So it was a pretty frightening experience?

Abstract/Evaluation:

69 CG12.1: Ah eh both time /But dis time was not quite as bad because
 70 we could see it coming /But de first time /De bad one dere /We
 71 couldn't see it coming

Orientation:

71 /Like at two o'clock in de morning

Evaluation:

71 /Y' like ah
 72 you know /When a person get up to go de bathroom /an dey can't
 73 make it back here

Complicating Action:

73 /We had to get a pail 'n /let him do his business in
 74 de bed eh

Evaluation:

74 /Because I'm not ah /In hospital /I don't have a bedpan or
 75 /like //You know

76 PAT: Yeah] yeah yeah

Evaluation:

77 CG12.1: An for him to let me an his daughter do dat for him /he
 78 had to be pretty bad /Because he's a pretty proud man
 79 PAT: Yeah yeah yeah

This second story about the "November" acute exacerbation event again provides an example of the role of near-death events in the understanding of the meaning of acute exacerbation events. Once more CG12.1 begins her story by comparing this

present admission with what appears to have been a previous unique acute exacerbation experience:

69 CG12.1: Ah eh both time /But dis time was not quite as bad because
70 we could see it coming /But de first time /De bad one dere /We
71 couldn't see it coming

In the above evaluation phrases, CG12.1 suggests that the near-death event—"De bad one dere"—was a new experience that took the family by surprise. CG12.1 states that the acute episode occurred in the early hours of the morning—"two o'clock in the morning". Inclusion of this orientation information, in part, also reinforces the uniqueness of this experience for this family caregiver.

This account, however, does not contain all the structural elements of a death story, but rather, in the context of the total interview, appears to have been presented as an extension of the CG12.1's first near-death story. CG12.1 is talking about the same acute exacerbation event, but in this telling only includes details describing her husband's distress before she and her daughter sought help. CG12.1 does not talk about breathlessness, but rather, in the orientation and narrative phrases, tells of the physical limitations experienced by her husband. The severity of the dyspneic experience is implied in the graphic details recounted in the narrative phrases:

73 /We had to get a pail 'n /let him do his business in
74 de bed eh /Because I'm not ah /In hospital /I don't have a bedpan or
75 /like //You know

In the story's concluding evaluation phrases CG12.1 states that the point of this story was to describe the severity of her husband's illness (intractable dyspnea). Her inclusion of personal details relating to toileting implied that this was the evidence that convinced her that P12 was indeed in acute (respiratory) distress. She reinforces her presentation by suggesting that her husband was as ill as he was proud—"pretty bad", "pretty proud":

77 CG12.1: An for him to let me an his daughter do dat for him /he
78 had to be pretty bad /Because he's a pretty proud man

Both stories outlining this near-death experience vividly describe an experience of near-death that clearly was a watershed experience for this family caregiver.

Summary

The preceding patient and family caregiver death stories described the experiences of acute exacerbation events for members of two family units. Although the circumstances of the breathlessness episodes were unique to each participant, they were presented as examples of the story structure, content, and evaluation elements of near-death and shadow-of death narratives seen in eight of the ten cases in the data base. These death stories shared a broadly common structure and meaning. In both types of death stories storytellers talked of their fear of death or dying. In addition, each story excerpt demonstrated that near-death acute exacerbation episodes represented an unequivocal change in the participant's understanding of intractable dyspnea, and as such functioned as watershed experiences in the patient's or family-caregiver's understanding of uncontrollable dyspnea requiring hospitalisation. These stories also revealed that individuals who had experienced a near-death acute exacerbation event then referred to the near-death event when describing subsequent dyspneic episodes. Indeed, stories of ensuing episodes of breathlessness included talk of death and dying. These participants now lived in the shadow of their near-death experience that clearly marked the boundaries of their incapacitating illness as they understood it. These stories also begin to illustrate the centrality of the acute exacerbation events in the patients' and family caregivers' understanding of this chronic illness.

CHAPTER 7

VULNERABILITY STORIES

"When your lungs don't work your legs don't work"

"It's scary /when you can't breathe"

In their conversations about acute exacerbation events, the patients and their family caregivers in this study told numerous stories that described the relationship between acute dyspnea and the patient's physical and emotional functioning as they lived with their chronic lung disease. The most frequently told stories across the interviews related to unusual breathlessness and the patient's emotional functioning (see Table 6, Appendix A). Patients talked of their experience of functional disability on an everyday basis and during episodes of unusual dyspnea that required emergency hospitalisation. Family members told stories about the patient's physical and emotional disfunction in their role as caregivers.

In these stories patients and family caregivers represented physical and emotional disability as a sense of vulnerability: a vulnerability experienced by the COPD sufferer during and in anticipation of episodes of increasing or intractable breathlessness; situations they were unable to avoid or effectively manage. I have categorised these stories of physical and emotional disability as "vulnerability stories".

As I examined these accounts I again identified common structure and content elements. In most vulnerability stories patients and family caregivers included a description of the patients' experience of dyspnea or its sequelae, their physical or emotional functional limitations, and an account of the resolution of the story events.

The resolution segments commonly included help-seeking behaviour such as emergency hospitalisation. They talked of their experience of severe physical or emotional disability as a distressing event.

In these stories patients and family caregivers represented the relationship between physical and emotional functioning and breathlessness as both circular and complex. In a number of stories participants talked of physical and emotional disfunction as being a result of both chronic breathlessness and increased physical or emotional activity. In other stories the relationship between physical and emotional functioning and unusual breathlessness was unclear. In stories where the cause of breathlessness was ambiguous participants talked of physical or emotional disfunction as a sign of intractable breathlessness.

It became apparent that the telling of stories of physical and emotional disability—stories describing the patients' inability to walk, talk, or become angry because of intractable breathlessness—functioned to make the subjective invisible experience of breathlessness visible. This process of giving concrete expression to the dyspneic experience also functioned to legitimise the illness (physical and emotional disability) and help-seeking behaviour of both the patients and their family caregivers.

In the following section I will consider the structure, content, and function of patient and family caregiver vulnerability stories in more detail. The initial purpose of this discussion is to explicate further my definition of physical and emotional vulnerability stories. The process is also intended to highlight how analysis of the structure and content of these stories as vulnerability accounts contributes to the understanding of acute exacerbation episodes of COPD characterised by unusual dyspnea as described by patients and family caregivers.

Vulnerability Stories: Structure and Content

Before examining these stories in detail, it is perhaps necessary to describe the concept of vulnerability as used in the context of these accounts. In the following analysis vulnerability will be understood as the individuals' (patients') perceptions of their lessened potential or capacity for interacting with perceived challenging or threatening environments (Clarke & Driever, 1983.). The conceptualisation of vulnerability as the innate or acquired capacity to be injured or hurt is described by other nurse-researchers in their work with adolescents (Hogan & DeSantis, 1994), psychiatric patients (Zubin & Spring, 1977), women's health issues (Steven, Hall, & Meleis, 1992), families (Demi & Warren, 1995), and geriatric patients (Good & Rodrigues-Fisher, 1993). It is a subjective and invisible experience (Anthony, 1989; Cohler, 1989; Rose & Killien, 1983).

As indicated, participants told stories of events describing physical and emotional functioning during episodes of unusual breathlessness. I therefore analysed patient and family caregiving stories according to these groupings. Two stories are initially presented as examples of these physical and emotional vulnerability accounts. They are sections from more complete narrative segments to be examined in detail at the end of the chapter. One part of P8's interview, shown below, is an example of what I have categorised as a physical vulnerability story. P8 was a retired machinist. In his youth he had lived and worked on a farm. He now suffered from COPD characterised by acute episodes of dyspnea requiring emergency hospitalisation. In the following story this patient describes the relationship between his decreased physical capacity and his incapacitating shortness of breath. His story portrays his present sense of physical disability and vulnerability.

Physical Vulnerability Story

An we used to run

P8

- 85 P8: And ah neighbour of mine /we used to just /for practice /[h] This
86 there was a store /about three miles down /and we'd both run there
87 /Say "Let's let's run" /"See if" [h] /"How how..let's ah that" /Ah you
88 know /You can maintain that /[h] Ah running eh
89 PAT: Umhum
90 P8: An we used to run to that /Have a /Have a /Buy c' candy or
91 chocolate bar or /Do the same thing /Run back eh /You know
92 anything to to... /To s' or anything to do like eh
93 PAT: Yeah
94 P8: Because ah /Well farming was always some /oh some profession
95 eh
96 PAT: Yeah
97 P8: So...so now [clears throat]
98 PAT: But now //running is not?
99 P8: Eh] /Oh I just just thinkin' about that now /I NEVER /[h] Well I
100 ah if I walk a block that that plays me right out /I gotta stop /[h] I
101 gotta take my breath back you know
102 PAT: Yeah
103 P8: Even standing up /[h] bothers me /Oh knock the hell out /[h] It
104 bugs the hell out of you

The following segment of P10's interview is an example of an emotional vulnerability story. P10, a retired miner, was also admitted to hospital with an acute exacerbation of his chronic lung disease. In this story he talks of his inability to predict or control his emotional reactions to circumstances of every day life. He is emotionally vulnerable:

Emotional Vulnerability Story

Your emotions your emotions

P10

Abstract:

- 129 P10: /An that happened to me before /Was I was ah
130 /..[h] sittin' down watching /[h] ah a rodeo [taps table] /out ah
131 Alberta /[h] This kid [taps table] was on a horse /Didn't know him at
132 all ah /W' why should I know eh /just a kid on a horse /[h] But he
133 fell off /an I was just /big tears comin' down like that /[h] [taps
134 table] But I was out of oxygen /I didn't know it /..My daughter was
135 there too /[h] My other daughter was there /an I started to cry /So I
136 called her over [h] [taps table] /I says "What the hells this" /I says "I'm
137 crying" I said /"Because this kid fell off the horse" /[h] [-h] you
138 know /So she checked my monitors /They were at em' They were at
139 empty/So [h] I went to the hospital /got it refilled eh /that's what it
140 takes eh
141 PAT: So it really affects and changes you
142 P10: Um?
143 PAT: Changes you

144 P10: Yeah /it does it does /your emotions your emotions /[h]
145 yeah..yeah /it does a lot of things /does a lot things to ya

Although the dyspneic behaviour described in the above stories appears to have different causes (one physical activity, the other emotional distress), the narrative phrases share a common structure: i.e., phrases talking about dyspnea or phrases portraying some form of physical or emotional disfunction or both, and phrases describing the outcome or resolution of the narrative event. In addition the evaluation segments of these stories usually identify the relationship between breathlessness and physical and emotional disability. The following discussion will address these common elements in both physical and emotional vulnerability stories. In addition, examination of the structure of these stories as well as those identified in the patient and family interviews will assist in interpreting the function of these accounts as physical and emotional vulnerability stories. The following excerpts will again show that a variety of rhetorical devices and discursive strategies were used by the participants to communicate the dyspneic experience as physical and emotional disability.

Dyspnea and Physical Activity

As in the above story excerpts, an explicit or implicit reference to dyspnea was included in all vulnerability stories. In stories describing physical functioning the patients and family caregivers talked of dyspnea or its sequelae: i.e., the fatigue and weakness associated with increasing shortness of breath. In physical vulnerability stories participants talked of the presence of increasing dyspnea that made previously simple physical tasks such as walking and speaking impossible. In these accounts the participants sometimes described the physical sequelae as evidence of the subjective experience of intractable breathlessness.

As highlighted in the following short excerpts from a variety of interviews, patients', and family caregivers' repetition of words or phrases—"bad", "he doesn't do anything"; use of intensifiers—"so weak", and inclusion of direct quotations, emphasised the degree of physical disability that patients experienced because of their shortness of breath:

P3

8 P3: Eh] /an [-h] I stard to cough /but that too **bad** /[-h] But not as **bad** a
9 cough /[-h] [-h] An I I fell down

P3

239 P3: I couldn't talk a /[-h]

CG3.1

37 CG3.1: Well this time he was s' **so weak** when after he cough /An
38 dis he said "**I I don't know /I just can't walk /I can do nothing**" /An I
39 see for myself dat he was really weak

P5

65 P5: /I start to shake more /I can
66 do less around the house like /Walk /Ah when the time comes that /If
67 it's..I make something to eat /an I..I have no appetite to eat it

CG5.1

291 CG5.1: /We're usually
292 there pre'-one of us is usually present with my dad /because he's in
293 he's in um /ah like a crisis situation /He can't y'know talk /So we do
294 /We answer a lot of the questions [bangs table] /an ah [bangs table]
295 that [bangs table] for [bangs table] him

CG8.1

119 CG8.1: **He doesn't do anything** [laughs] /In ah summer time /he
120 putters around in the yard /Ah in the garage /But in the no' now /**He**
121 **doesn't do anything** /He might go down to the basement /Putter
122 around down there /But ah **he doesn't do nothin'** that's strenuous or
123 nothing /No

P9

79 P9: /I called her and I said "**Couldn't**
80 **talk any more**" /So she just ah said I have to go to de emergency

In several stories participants talked of the relationship between breathlessness and physical functioning. In their stories they suggested either that an increase in physical activity escalated usual breathlessness or that the experience of unusual breathlessness resulted in physical disability necessitating a cessation of physical activity. As the

following segments illustrate, this causal association between physical activity and dyspnea was clearly circular in nature. In some stories this reciprocal relationship was stated explicitly. In others the circular nature of the relationship between unusual breathlessness and physical disability was implied.

Both patients and family caregivers, as highlighted below, again emphasised the causal association between dyspnea and physical activity by repeating words that indicated that the patient had over extended themselves—"too far", "not far", "far enough", and using word intensifiers—"really beat", "very hard". In addition, quantifying the patient's level of disability also strengthened the claim that as breathlessness increased physical functioning decreased: i.e., managing only "two steps" instead of the usual "four", doing nothing for "10 minutes", and carrying only "one" bag of groceries:

P8

99 P8: / [h] Well I
100 ah if I walk a block that that plays me right out / I gotta stop / [h] I
101 gotta take my breath back you know

CG7.1

193 CG7.1: /When she [P7] comin' in the room /den she want in
194 washroom /I help her to go there /and ah nurse says "**You want help**
195 **/I help you**" /She says "**No**" /She went in /an she cannot get out /So
196 we have t' ah go in /an **help** her to /to go out

CG8.1

80 CG8.1: ...One time he was out in the garage
81 /Workin' around in there /An he came in an he couldn't breath /Ah he
82 **just just** about made it in the house

P9

16 P9: /Just ah sometime get outa the bed and ah /go
17 to the bathroom /Sometimes **too far** is **not far** /because it's **far**
18 **enough** /I have to sit down /and break my pattern /Between the
19 place maybe [hh] **fifteen feet** away /That's all

P10

50 P10: /I was **really**
51 **beat** when I got there [h] /so ah [h] I **couldn't** even talk to the [h]
52 regis' registered nurse / [h] [h] I had t' just [laughs] say yes an no an
53 then [h] [taps table] /**Didn't** have the power to even speak / [h] until
54 I sat down for [taps table twice] /maybe **ten minutes** /Then I can [h]

55 relax enough that it'll /Feel **won't** be too bad eh /[coughs twice]

CG10.2

89 CG10.2: /I've seen him stop /make **two**
90 **steps** /an stop and take a breath /when he's **really really bad** /You
91 know what I mean
92 PAT: Yeah
93 CG10.2: Ah /..On normal circumstances /**four steps** are /enough for
94 him /But when he's **really sick** /he **really** has a hard time /He huffs
95 and puffs /He has a **very hard** time catching his breath

P12

36 P12: I'm short of bread 'n [h] /every like ah /[h] If I ah
37 come home /she got groceries /[h] I bring **one bag** in /[h] I gotta sit
38 down an take a puffer /An I can't even go out an ah /[h] help her
39 anoder one /[h]

Other physical vulnerability accounts described the changes in physical functioning as a result of dyspnea by telling contrast stories. On occasion, as highlighted in the following story segments, the patient or their family caregiver simply talked of what the patient was able to do before becoming sick—"he was on the farm", "she used to", "he used to". The repetition of these phrases and the use of word intensifiers—"really really really hard", "very active", "HUGE garden"—emphasised the family caregivers' descriptions of the changes in the patients' physical functioning:

CG3.1

304 CG3.1 /h' he [P3] was on the farm
305 /an he work **really really really hard** /His modder was very
306 young /I I in October /at the end of October /an in November at the
307 end of November his dad went to Montreal t be with her /an leave
308 four kids alone /He was 13 /The odder one too 12 /An the odder one
309 10 /H' he leave dose four kids alone /An he was the one who was
310 looking /at the kids and looking at all the work he had to do /An in
311 dat time his dad never make dem any ah wood ahead of time
312 /Nothing /He was doing everyting /He went to school beside dat /so
313 he's stay up most of the time at night time /an an try to read and do
314 hi s own house in his own time

CG7.3

87 CG7.3: ... She was always /She was **very active** /She used
88 to go out /they have a **HUGE garden** in the back yard /She used to
89 go out and shovel it by hand /She used to do everything /and now

CG12.1

346 CG12.1: Well he was of /he used to go for his walk for de mail /An
347 he goes across /get his paper an /He used to come an do de
348 shopping wid me an /like you know

In a number of physical vulnerability stories the contrast between present levels of functioning and past ability was made explicit. Here the participants explicitly talked of the patient's current level of activity in comparison to their behaviour before they became chronically ill. As shown below, they told of the patient's inability to function as they once did—"He [I] used to", "he [I] can't". Again the inclusion of specific details quantifying activity levels—"ten steps", "50 pounds"—emphasised the change in the patient's physical functioning:

CG5.2

226 CG5.2: Like up until just a few years ago he walked around the block
 227 /Three or four times /EVERY night he'd do a str'-you know /He'd an' at
 228 a good clip /You know /It was good exercise for him /**He used to**
 229 bowl /**He used to** ah he used to be very active in different things
 230 /Veteran's Affairs an /You know /An he does nothin' now /'cause he
 231 can't /It's it takes all of his strength to get up from the bed and walk
 232 like the **ten steps** to the computer and he'll rest there for a bit /An
 233 then it's another **ten steps** or so to the kitchen chair /An he'll rest
 234 there for a bit /An then /it's about another **10 steps** or so ah to go to
 235 the bathroom

CG10.2

610 CG10.2: /They travelled every where /..So when when
 611 when she [P10's wife] passed away /it hurt /He was left alone /He's tried to do
 612 what **he can** /**He can't** do it /An it it /An it's getting worse /Where **he**
 613 **can't** do anything anymore

P11

235 P11: /**I used to**
 236 work /...Hour after hour in the mine /[h] Some days I'd go to work
 237 on Saturday morning an come home Sunday night /[h] And all of a
 238 sudden /[h] To be thrown off work /An I can't carry on /[h] **50 pound**
 239 bag of potatoes in the house /Do you understand what I mean?
 240 PAT: Umhum
 241 P11: It's..it's **very inconvenient** /And **very hard** on the nerves

In some vulnerability stories, as illustrated in the following excerpts, participants explicitly talked of the patients' realisations of their physical limitations in situations where they would have previously been able to protect themselves: everyday situations, like sitting outside or alone in their own home. In two of the following examples the use of direct quotations emphasised the patients' present sense of physical vulnerability based on their experience of physical disability associated with

incapacitating dyspnea:

CG5.1

231 CG5.1: Ah he got a scooter /He went on it once /And it scared him
232 /I tried to get him out this past summer /Like just even to sit outside
233 on a lawn chair /But he was he was afraid /Afraid of catching
234 something

CG5.2

605 CG5.2: ... He has a pellet gun /right beside his chair in the kitchen /An
606 I've said **"DAD [soft chuckle] you can't ever use that or point it at**
607 **anybody"** /You know is it /You know **"This is this is an offensive**
608 **weapon dad /This is a firearm /It may be just a pellet gun /But it's**
609 **real"** /An um he saying **"Oh well just _____"** /You know /He
610 kinda get's blustery an /He just got a little ahm /a little alarm thing /A
611 motion sensor /For in the kitchen /For when he's in his bedroom

P8

234 P8: You see you gotta always /pace yourself
235 PAT: Yeah yeah yeah
236 P8: But ah /When I'm gonna walk a half a mile /Or ah two three
237 blocks [h] [coughs] /An if I don't haven't got ah er /I often leave the
238 house with no [h] no /Forget my puffers eh /..An if I'm driving down
239 the down the street /'Nit hits me **"Geez I forgot the puffers"** /[h] I
240 don't continue w' goin' where I'm goin' /[h] [coughs] I go back /And
241 get my puffers /An then I'm relaxed /to go

Dyspnea and Emotional Functioning

In emotional vulnerability stories, as in physical vulnerability accounts, the relationship between emotional actions and dyspnea was also presented as circular. In some stories the episodes of increasing or unusual dyspnea were described as having been triggered by the patient's emotional behaviour. The increasing dyspnea then evoked other emotional reactions and as a result more severe breathlessness. For example, several stories told by both the patient and family caregiver described everyday circumstances where emotional feelings unwittingly experienced by the patient played a part in the initiation of an acute exacerbation event. The psychological tasks described in these stories, as shown in the following examples, included activities such as arguing with a relative, getting angry, waiting for a late visitor, getting frustrated, or being in a crowd. These normal emotional reactions result in an

increase in shortness of breath:

P8

34 P8: Well ah /..sometimes it [*dyspnea*] starts through excitement /you ah [h] ah
35 especially when you're **you're mad** at somethin' /**You get excited** /[h]
36 an this ah makes /It don't make it any better /Makes it worse

CG8.2

73 CG8.2: /ah like **they** [*P8 and his wife (CG8.1)*] **argue** quite a bit
74 /and ah I think that has a lot to do with it //ah
75 PAT: He] gets upset
76 CG8.2: **He get's upset 'n /angry /frustrated /...then he gets short of**
77 **breath**

CG9.1

172 PAT: she's [*P9*] been doing more?
173 CG9.1: No she's not physical //but mentally
174 PAT: But] mentally /visiting /more people visiting or?
175 CG9.1: People visiting /an then people that should gonna came
176 Christmas day /they didn't come Christmas day //ah
177 PAT: Oh] she gets upset?
178 CG9.1: **She gets upset at any anything and everything**

CG10.2

235 CG10.2:Well if he's waited too long /....I don't know /I guess he
236 scares himself /you know when he **panics** /it makes the matter
237 worse /...I don't know why he **panics** /though as soon as he start to
238 **panic** /it makes it all..ten times worse for him /an I don't know why
239 he does it

Some stories, as shown in the following excerpts, more clearly demonstrated that these patients and family caregivers were aware of the patients' acquired emotional vulnerability. They recognised emotional dysfunction as a part of their chronic illness. Indeed any increase or change in their emotional response was understood as a sign or marker of unusual breathlessness. Because of their experience of previous episodes of increased breathlessness they now recognised a sense of panic, for example, as a sign of potentially intractable dyspnea. As illustrated in two of the following segments, patients and family caregivers who understood their "panic" behaviour as the indicator of potentially intractable dyspnea, initiated help-seeking strategies when they recognised increased emotional dysfunction—"OK I've gotta go in the hospital", "so I'd called Medigas":

CG5.2

56 CG5.1: /he he often he waits until
57 he's ah /..ah he gets **panicky** /an I'm sure that doesn't help with the
58 breathing process /he can't relax enough to /to get anything in/an
59 he starts getting panicky /an he realizes /"OK I've gotta go in the
60 hospital" /he ah [taps table] he waits [taps table] an he waits [taps
61 table] an he waits [taps table]

P10

103 P10: /I went
104 in a **panic** one time /at home three o'clock in the morning /I
105 thought I was gonna go crazy /so I'd called **Medigas** /Something
106 happened to my tank /I couldn't /[h] wasn't getting [taps table] no
107 oxygen

P10

119 P10: /An I was SO..um /how
120 would you say that? /ahm...[-h] T' find I wanted so much to find
121 those papers for her [taps table] /that it got me all upset

P10

373 P10: ..oh it's hard /[h] **I can't stand crowds**
374 [taps table] /I go in--I tried to go at the bos--b' basement of the
375 church an play cards /on a Friday afternoon /So I tried to go down
376 there an [h] play cards /Oh I got down alright /but the people /You
377 just [h] like this /An nobody smokes though /[h] but the crowd /[h]
378 seems to ah [taps table] /I don't know what it does but ah /can't
379 stand crowds

The Resolution

Both physical and emotional vulnerability stories generally concluded with an acknowledgement of the patient's physical or emotional disability, a decrease in the patient's activity, an increase in the patient's experience of dyspnea, further emotional distress, and/or often some form of help-seeking action. As the following story segments illustrate, the help-seeking behaviour described often included emergency admission to hospital:

P5

409 P5: /So she [P5's daughter] phones then the ambulance
410 /and explained what the score was /..An she got a bag already for
411 me /..Ah..made sure my phone was back on on the cradle /because
412 it's a battery operated thing /Ah..and just kept-shut off the oxygen

CG5.2

64 CG5.2: /He [P5] waits 'til one of us gets there
65 before he calls the ambulance /He can't make it in a car

CG8.1

23 CG8.1 /Well it
 24 just go so bad that he couldn't breathe almost so /got an ambulance
 25 an took him there

P9

82 P9: Well dey [*P9's daughter and son-in-law*] bring me /aah call de ambulance eh

CG8.1

126 CG8.1 /He sits there at
 127 the ah lunch counter /at the lunch ah ca' at the cafeteria /and he sits
 128 there and he waits for me

P11

249 P11: /he [*P11's son*] always does that [*fixes his car*] for me

CG12.2

716 CG12.2: /an I take
 717 off his [*P12*] boots an that /I don't let him /to bend down

Vulnerability Stories: Meanings and Function

Before proceeding with a description of the function of vulnerability stories it is necessary to examine the explanations presented by the participants for telling stories about patients' physical and emotional vulnerability. As already suggested several analogous evaluations phrases were identified across the patients' and family caregivers' vulnerability stories. The most frequently presented explanation was to communicate that the patients, because of their chronic lung disease, were physically and emotionally vulnerable and that acute episodes of breathlessness or the threat of increased dyspnea further exacerbated this physical or emotional dysfunction. In these stories it was clear that patients who were already physically and emotionally disabled were unable to undertake normal physical or emotional activities because of the threat of increased breathlessness and its sequelae, or experienced increased physical and emotional dysfunction during episodes of increased dyspnea.

As the following evaluation segments show these complex circular understandings were included by both patients and family caregivers. The participants' use of

rhetorical devices such as repeated words and phrases—"gotta", "he can't do anything", "he'll force himself to do it", intensifiers—"just" "even", and attention to detail—"three or four stairs", "a block", emphasised the degree of functional disability normally experienced by the patient:

CG5.2

235 CG5.2: /but that's all he can do /he can... sometimes
 236 m'manage a few stairs /he's got **three or four stairs** to go into his home /an
 237 he can manage those /but um he hasn't been out of the house
 238 for...close to **three years** /like except for going to the hospital /or
 239 doctors appointments //and that's it

CG5.2

407 CG5.2: **He** can't do anything /he can't do anything

CG5.2

418 CG5.2: /he just he CAN'T DO IT /but he'll he'll like **he'll force himself to**
 419 **do it** /and **he'll push himself to do it** /but he'll be wiped

P7

163 P7: /when you short it's not everything [h] /not much
 164 you can do

P8

99 P8: /[h] well I
 100 ah if I walk **a block** that that plays me right out /I **gotta** stop /[h] I
 101 **gotta** take my breath back you know
 102 PAT: Yeah
 103 P8: **Even** standing up /[h] bothers me

P9

163 /P9: just ah just ah sit in my chair /close close to de de bed ah /yeah

For both patients and family caregivers the point of other stories was to illustrate the reciprocal and escalating relationship between the patient's anxiety or panic behaviour and the resulting respiratory distress, a dyspnea-anxiety-dyspnea cycle:

CG8.1

83 CG8.1: /I think the whole problem is /is that when he
 84 starts having a **little** bit of a breathing problem /he gets excited /and
 85 then he panics /..an then he **really** has problems

CG9.1

165 CG9.1: I I think she is yeah /I would think dat's one of the biggest
 166 problem /An the more she gets excited /**the worse the worse** her
 167 breathing gets

Both patients and caregivers found the circumstances of potentially unmanageable

breathlessness distressing. Indeed, patients concluded their stories by saying that the anticipation and experience of such limited functioning because of incapacitating dyspnea was emotionally difficult. As highlighted in the following segments, their sense of distress was expressed as emotional vulnerability—it was "too hard", "too much", "very scary". They "cannot die/cannot live":

P7

70 P7: Getting **too harder** for me /First time I be younger an fighting
71 /Now it's **too hard** speak of it /I **just** want to cry

P7

81 P7: /wasn't like that
82 before /I never was was not scare of nothing /an' I do everything
83 that I want to do /Now I not do nothing /...only suffer

P7

152 P7: I **cannot die** /I **cannot live** /I not scared of dying /Scare [h] of
153 the pain /an lack of air /**Too much** to take [cries]

P9

136 P9: yeah **you you scare you**
137 know /too y' you don't want to be alone

P11

19 P11: ... it's **very scary** /or if you can't get your breath /An it's **thirty miles**
20 to ah /[h] the emergency hospital /[h][--h] [h] [--h] [h] [--h]

P11

278 P11: Oh yeah /[h] definitely /like **I couldn't** live alone /**I couldn't** go
279 and live in an apartment by myself

Family caregivers on the other hand, when recounting stories of the patient's physical and emotional vulnerability, concluded their accounts by expressing their sense of helplessness—"you cannot do nothing", "you feel sort of helpless"—and fear when present during an episode of acute dyspnea—"it's it's scared me", "you panic":

CG5.1

163 CG5.1: [I said] "Dad /you're going to the hospital now" /because i'it's it's
164 scared me

CG7.1

105 CG7.1: No cannot do nothing /you can no breath /you says "**Calm**
106 **down** /**calm down**" /how you **calm** down if you got no air? /that's
107 terrible

CG7.2

56 CG7.2: /you're sort
 57 of /you feel sort of helpless /You try to help them /an you panic

CG8.1

197 CG8.1: I wasn't frightened /I just wanted to get him there /an ah see
 198 that he got the proper care an that /because **there's nothing I can do**
 199 /for him

CG9.1

72 CG9.1: There's nothing we can do /dat's dat's the sad part of it /and
 73 I think dat's why **she gets afraid**

CG10.1

36 CG10.1: **Nothing I can do** /I just make sure he doesn't do anything

CG12.1

193 CG12.2: I do /I **get all panicky** [laughs] /because I don't know
 194 what's gonna happen /to him

Family caregivers found it not only difficult to watch an acute experience of breathlessness, but also talked about the seriousness of future dyspneic events—their "biggest fear". They suggested through their stories that the patient would ultimately die—"choke", "not gonna make it"—during one of these events:

CG5.1

461 CG5.1: Like my **biggest** fear /an CG5.2 will tell you this is that
 462 /he is goin' /He well /An which in all likelihood he will probably
 463 suffocate to death

CG5.2

183 CG5.2: ..I feel a lot of guilt /actually when I
 184 see him like that [gasping for breath] /'cause **I don't wanna be there /I don't wanna be**
 185 **there** when I see him like that /**I don't want** to see that //you know

CG12.1

178 CG12.2: I don't know if he's gonna **choke** to death
 179 /or if he's...you know /I don't know /because I have ah f' ah friend
 180 here /her father had emphysema /and he died /an he **choked**

CG8.2

33 CG8.2: I know one of these times he's /he's
 34 not gonna make it

Finally, in another group of evaluation segments from vulnerability stories, family caregivers talked of their sense of relief and security once they decided to seek help or the patient arrived at the hospital emergency department. On occasion these participants suggested that the patients shared this sense of relief. This feeling of safety

was sometimes coupled with talk of an improvement in the patient's physical condition:

CG3.1

39 CG3.1: /umm I
40 said "D' have to-no choice /I have t' bring 'im [*to the hospital*]"

CG5.1

322 CG5.1: I mean
323 'm I feel quite confident /You sleep well at night when he's in the
324 hospital /Yes I know he's being taken care of /an if there is an
325 emergency /he will be looked after

CG5.2

643 CG5.2: I think he feels safer
644 in the hospital /It's become a very familiar environment to him /over
645 the past few years /He ah it's not that he's been in there more than
646 he's been out /but ahm he's been in a lot

CG8.1

209 CG8.1: Well he was still havin' problems breathing /but he felt he
210 felt better /'cause he knew he was some place where they're going
211 to look after him /do the proper thing for him

CG12.1

133 CG12.1: /I radder see him dere /an be healty /like you
134 know /as much as he can
135 PAT: Umhum
1361 CG12.1: 'Cause I don't want to lose him right now

In summary, in the participant stories that included talk of physical and emotional functioning during or in anticipation of unmanageable dyspnea there were a number of related meanings. For patients, the stories communicated their understanding of the reciprocal relationship between dyspnea and their physical and emotional disability. Through their stories they conveyed the sense of helplessness and suffering they endured as they lived through dyspneic experiences. These patients also communicated their recognition of the complex relationship between physical and emotional behaviour and unusual breathlessness: i.e., that dyspnea can on occasion precipitate emotional as well as physical dysfunction, a dyspnea-anxiety-dyspnea cycle. Family caregivers also communicated their understanding of the complicated relationship between patients' dyspnea and their physical and emotional behaviour. Their stories

suggest that they too recognised that patients were compelled to control their emotions and reduce their physical activity both in situations of everyday life and in circumstances of increasing breathlessness.

Visibility Function

In the above story excerpts physical and emotional dysfunction were often presented either as the sequela of unusual dyspnea or as the visible expression of the patient's subjective experience of breathlessness. In stories of physical vulnerability patients were portrayed as being physically disabled: i.e., because of their breathlessness they were often unable to talk or walk, could not do normal activities of daily living (personal grooming, carry in the groceries), and complained of extreme fatigue with minimal exertion. In stories of emotional vulnerability patients were presented as individuals who normally could not express common emotions (anger, sadness, fear, frustration) without either precipitating breathlessness or exacerbating already existing dyspnea potentially to the point of physical collapse. The representation of breathlessness as physical and emotional disability made this subjective invisible experience visible. When participants talked of patients' inability to walk or even talk because of their breathlessness they provided concrete images of the reality of unmanageable dyspnea during acute episodes of COPD.

P8

99 P8: / [h] Well I
100 ah if I walk a block that that plays me right out /I gotta stop / [h] I
101 gotta take my breath back you know

P10

135 P10: /an I started to cry /So I
136 called her [*my daughter*] over [h] [taps table] /I says "What the hells this" /I says "I'm
137 crying" I said /"Because this kid fell off the horse" / [h] [-h] you
138 know /So she checked my monitors /They were at em' They were at
139 empty

Legitimisation Function

Such vulnerability stories give the subjective experience of breathlessness an interpretable form. In their stories patients measured the seriousness of their dyspnea concretely: i.e., by how they felt and by what they were able to do. Patients and family caregivers communicated how they understood unmanageable breathlessness; both physical and emotional dysfunction and vulnerability were part of their experience of living with chronic lung disease characterised by acute exacerbation events. By giving dyspnea a visible form they also inherently legitimised the patients' complaints of this invisible experience (feeling short of breath) and their help-seeking behaviour. Breathlessness concretely represented as physical and emotional dysfunction and vulnerability functioned to legitimise the experience of dyspnea.

Two longer segments of narrative texts are now presented as examples of patient vulnerability stories. Like other participants in the study, each teller recounted physical and emotional vulnerability stories and described their understanding of acute dyspnea as being an experience inextricably related to physical and emotional functioning. Their narratives are presented to illustrate the application of a Labovian framework in the identification of distinct story units (Labov, 1972), to demonstrate the identification of vulnerability stories, and to explicate the analytical utility of these vulnerability story structures in interpreting the participants' understanding of acute exacerbation events. Most importantly, these examples will illustrate the function of vulnerability stories in making dyspnea visible, and as a way of legitimising the help-seeking behaviour of patients and family caregivers during experiences of acute breathlessness.

Case Example #3

P10, a 73 year old retired miner, had been admitted to hospital frequently over the last six years with acute dyspnea. He had the characteristically barrelled chest of an individual with longstanding chronic obstructive pulmonary disease and during the interview was unable to finish a sentence without taking a breath. He had been on home oxygen therapy for several years and was bothered by a productive cough that worsened with acute exacerbation episodes. During our conversation P10 spoke very softly. On several occasions his eyes filled with tears as he recounted the stories of his illness.

P10's wife died suddenly seven years ago. He suffered his first acute episode of chronic lung disease in the year following her death. That admission was a watershed near-death event characterised by a prolonged hospitalisation and marked the first of several subsequent admissions for acute respiratory distress. He nevertheless continued to live in his own home. Immediately following this near-death experience P10 lived alone. Approximately six months later his grandson (CG10.2) and young family moved into the self-contained apartment on the second floor of P10's home. In my conversation with P10 and his grandson I found that a very warm relationship characterised by mutual respect existed between these two men. Six months before this admission P10's grandson bought his own home and one of P10's daughters and her two teenage sons subsequently moved into the vacated apartment. This daughter (CG10.1) replaced the grandson as the primary family caregiver. However, whenever CG10.1 was not home, P10 continued to phone his grandson for assistance.

CG10.1 and CG10.2 both told stories of the events precipitating P10's present admission to hospital. According to them, P10 had driven his truck to a town

approximately three and a half hours away to celebrate the Christmas holidays with his extended family. Having his truck equipped with portable oxygen allowed him to drive alone. However, shortly after his arrival at his daughter's home, P10 realised that he was becoming more and more breathless. According to his grandson and daughter, P10 was unsure if his increasing dyspnea was due to his family's smoking or his inability to cope with the increased number of people. P10 immediately drove himself home, apparently hoping that the drive would be relaxing and ultimately relieve his respiratory distress. However, the next morning P10 realised that his dyspnea had worsened and asked his daughter (CG10.1) to drive him to the hospital.

The following is the full text of three narrative segments from P10's interview. The first, a physical vulnerability story, describes one aspect of P10's present admission to hospital. The second segment is composed of three emotional vulnerability stories. These accounts describe three unrelated episodes of acute breathlessness. The last segment, a story told near the conclusion of the interview, describes another situation of emotional vulnerability.

The stories are again presented using Labov's method of transcription and structural categories. The discussion will illustrate the utility of interpreting these accounts as physical or emotional vulnerability stories in the process of developing a more adequate interpretation of how these patients understood acute exacerbation events of breathlessness. Analysis of their structure and content gives some insight into the complex nature of the sense of vulnerability experienced by these participants during or in anticipation of acute dyspneic events:

P10: Physical Vulnerability Story

Didn't have the power to even speak

Story Stimulus:

47 PAT: So what happened? /Just got short of breath?

Orientation:

48 P10: Just short of breath an ah /an then decided to come over

Complicating Action:

49 /Daughter drove me over /I walked from the /[h]..handicapped

50 parking..spot there into the /[taps table] registration 'n

Evaluation:

50 /I was really

51 beat when I got there [h]

Complicating Action:

51 /So ah [h]

Evaluation:

51 I couldn't even talk to the [h]

52 regis' registered nurse

Complicating Action:

52 /[h] [h] I had t' just [laughs] say yes an no

Evaluation:

52 /An

53 then [h] [taps table] /didn't have the power to even speak

Complicating action:

53 /[h] until

54 I sat down for [taps table twice] /maybe ten minutes

Evaluation:

54 /Then I can [h]

55 relax enough that it'll /feel won't be too bad eh /[coughs twice]

Resolution/Evaluation:

55 /But

56 I sat there for [taps table] /15--20 minutes before [h] she called me

57 in to get registered again [h] /And I had to wait another half hour

58 /so there'd be an empty bed in the in the [h] emergency room [taps

59 table] eh

Evaluation:

59 /[h] Not--that was a long wait for me

This complete story was told in response to the initial interview question about what happened during P10's current admission to hospital. The story begins with P10's brief acknowledgment that he had experienced shortness of breath and as a result decided to seek professional help. The initial orientation phrases and narrative phrases identify the emergency waiting room as the story setting. However, throughout the account P10's talk emphasises the extent of his physical limitations rather than his feeling of breathlessness.

As storyteller, P10 talks of how physically limited he was during this episode of

acute respiratory distress: i.e., after walking the short distance into the emergency department—"from the handicapped parking"—he needed to rest for an extended period before he was able to carry on even a minimal conversation:

49 /Daughter drove me over /I walked from the /[h]..handicapped
 50 parking..spot there into the /[taps table] registration 'n
 51 /So ah [h]
 52 /[h] [h] I had t' just [laughs] say yes an no
 53 /[h] until
 54 I sat down for [taps table twice] /maybe ten minutes

Within the body of the story P10 does not mention that he was short of breath. Rather, the evaluation clauses, interwoven between the above narrative phrases, only imply that P10's physical disability was a consequence of his acute breathlessness: i.e., dyspnea is presented as a sense of overwhelming fatigue and an inability to speak—his physical vulnerability:

50 /I was really
 51 beat when I got there [h] I couldn't even talk to the [h]
 52 regis' registered nurse

The use of rhetorical devices in the evaluation clauses such as repeated negative verbs—"couldn't", "didn't", "won't"—and the intensifier "very" strengthen P10's portrayal of this experience as one of acute distress.

P10's reference to time in a number of the evaluation segments, as highlighted in the following excerpt, further emphasises his sense of physical incapacity and hence vulnerability:

52 /An
 53 then [h] [taps table] /didn't have the power to even speak /[h] until
 54 I sat down for [taps table twice] /maybe ten minutes

In addition, in subsequent evaluation phrases, as highlighted below, P10's specific inclusion of the length of time between his arrival at the emergency department and his registration and eventual admission to an emergency room bed appear to suggest that, from his perspective, the seriousness of his illness was invisible to the emergency

room staff:

55 /But
56 I sat there for [taps table] /15--20 minutes before [h] she called me
57 in to get registered again [h] /And I had to wait another half hour
58 /so there'd be an empty bed in the in the [h] emergency room [taps
59 table] eh /[h] Not--that was a long wait for me

Throughout this story P10 portrays his illness not as breathlessness but rather as a physical disability that makes him vulnerable; he is physically unable to manage this situation without help. His descriptions during this experience of breathlessness as physical limitations, assist in making visible his intractable dyspnea and hence, to some degree, legitimise his help-seeking behaviour.

In the next extended narrative segment P10 talked about "what it was like when [he was] that short of breath". This trilogy of vulnerability stories vividly portrays P10's understanding of the relationship between his experience of dyspnea and his sense of emotional vulnerability. These stories address the subjective nature of dyspnea and its emotional as well as physical sequelae. Emotional distress is presented as both a sign and a consequence of acute respiratory distress:

P10: Emotional Vulnerability Story 1

It's scary /when you can't breathe

Story Stimulus:

99 PAT: What's what's it like /when you're that short of breath? /Can
100 you describe that for me?

Abstract/Evaluation:

101 P10:It's very hard to..not get into a panic

102 PAT: Yeah

103 P10: You've gotta be able to control that /An I've learnt that

Orientation:

103 /I went
104 in a panic one time /At home three o'clock in the morning

Evaluation:

104 /..I
105 thought I was gonna go crazy

Complicating Action:

105 /so I'd called Medigas

Evaluation:

105 /Something
106 happened to my tank /I couldn't /[h] Wasn't getting [taps table] no
107 oxygen

Complicating Action:

107 /And the guy that delivers my oxygen [taps table] /he

108 calmed me right down on the phone /Told me what to do

Resolution:

108 /[h] After

109 that I was alright

Evaluation:

109 /But ah [h] It it it's it's scary /It's scary /when you

110 can't breathe ah [short cough]

Coda:

110 /It's something to think about

111 PAT: Yeah

P10: Emotional Vulnerability Story 2

An you're you're..you're carried to crying

Abstract:

112 P10: Yeah /[h]...but ah it never happened to me before [h] since

Evaluation:

113 /'cause I /kinda learned to /[h] calm down when I get excited /I calm

114 down a bit eh /[h] Like I can't seem to..get excited about anything

Orientation:

115 /Like ah the VON [visiting nurse] was at the house the other day /[h] I couldn't find

116 her /her papers [h] [taps table]

Complicating Action:

116 /An I start lookin' for those papers

117 /An the [h] [coughs]

Evaluation:

117 /I know I was all up in [coughs]

Complicating Action:

117 /Well she had

118 to [h] tell me to sit down and be quiet [taps table] /"Never mind the

119 papers" /said "We'll get them the next time"

Evaluation:

119 /An I was SO..um /how

120 would you say that? /ahm...[-h] T' find I wanted so much to find

121 those papers for her [taps table] /that it got me all upset

122 PAT: Yeah

Resolution:

123 P10: An I just didn't cry

Evaluation:

123 /but [h] it was that close

Coda:

123 /an that's another

124 thing oxygen will do for you

Evaluation:

124 /[h] is if you run out of ox' /run out of

125 oxygen /[h] it affects your /ah emotions

126 PAT: Yeah

127 P10: An you're you're..you're carried to crying

128 PAT: Yeah yeah

129 P10: But it's awful

P10: Emotional Vulnerability Story 3

Your emotions your emotions

Abstract:

129 P10: /An that happened to me before

Orientation:

129 /Was I was ah

130 /..[h] sittin' down watching /[h] ah a rodeo [taps table] /out ah

131 Alberta

Complicating Action:

131 /[h] This kid [taps table] was on a horse

Evaluation:

131 /Didn't know him at

132 all ah /W' why should I know eh /just a kid on a horse

Complicating Action:

132 /[h] But he

133 fell off /an I was just /big tears comin' down like that /[h] [taps

134 table]

Evaluation:

134 But I was out of oxygen /I didn't know it

Orientation:

134 /..My daughter was

135 there too /[h] My other daughter was there

Complicating Action:

135 /an I started to cry /So I

136 called her over [h] [taps table] /I says "What the hell's this" /I says "I'm

137 crying" I said /"Because this kid fell off the horse" /[h] [-h] you

138 know /So she checked my monitors /They were at em' They were at

139 empty

Resolution:

139 /So [h] I went to the hospital /got it refilled eh

Coda:

139 /that's what it

140 takes eh

141 PAT: So it really affects and changes you

142 P10: Um?

Evaluation:

143 PAT: Changes you

144 P10: Yeah /it does it does /your emotions your emotions /[h]

145 yeah..yeah /it does a lot of things /does a lot things to ya

The above stories vividly describe three unique episodes of unusual shortness of breath. Although the circumstances of each dyspneic experience are different, all clearly outline P10's evolving understanding of the connection between physical and emotional functioning, the experience of unusual breathlessness and the feelings of emotional vulnerability. They accomplish this task, in part, by providing detailed descriptions of each dyspneic episode. In addition, the explicit accounts of physical and emotional behaviour make visible P10's subjective invisible breathlessness and his

resulting feelings of emotional vulnerability—a dyspnea-anxiety-dyspnea cycle.

In this group of explanatory stories P10 demonstrates that over the last few years he has "learned" a number of things about the circular relationship between his subjective experience of shortness of breath and his accompanying physical and emotional disability. He appears to have learned that: regardless of the cause, panic behaviour exacerbates his sensation of breathlessness; it is "scary" to be short of breath; both physical and emotional activity can cause him to be breathless; not having enough "oxygen" can make him cry inappropriately; and emotional reactions to shortness of breath are unpredictable and not necessarily controllable.

The first of the preceding vulnerability stories highlights P10's understanding of both the relationship between breathlessness and panic behaviour and the fright of not being able to breathe. P10 describes an episode of dyspnea that most probably occurred shortly after his near-death experience almost six years ago. As noted above, he had lived on his own for a short period after his discharge following his first hospital admission for respiratory distress. The orientation phrases of this story imply that the dyspneic event around which the first story is based took place during those early weeks when he was living by himself. One night, according to P10, he awoke unexpectedly "in panic". The orientation clauses imply that he was alone, and, because of his acute breathlessness, panicked:

103 /I went
104 in a panic one time /at home three o'clock in the morning /I

The narrative phrases that follow describe how, amidst his "panic", P10 called and received help to manage his acute distress. The narrative clauses outline how the assistance given over the telephone by a respiratory technologist managed to both "calm" P10 and allow him to restore his oxygen supply. These narrative phrases not

only tell about the story events but also perform an evaluation function. By referring to both physical and emotional help, P10 implied that, from his perspective, there is an association between breathlessness and panic behaviour. Hence, the assurance of appropriate assistance and resumption of an oxygen supply reduced P10's distress:

105 /so I'd called Medigas
107 /And the guy that delivers my oxygen [taps table] /he
108 calmed me right down on the phone /Told me what to do /[h] After
109 that I was alright

Moreover, in the evaluation sections that introduced the story, P10 implicitly suggests that a relationship between breathlessness and panic behaviour is inevitable; that he has, out of necessity, "learnt" to control his emotional response to feelings of dyspnea:

101 P10:It's very hard to..not get into a panic
102 PAT: Yeah
103 P10: You've gotta be able to control that /An I've **learnt** that

In the following evaluation clauses that suspend the narrative action, P10 clarifies the relationship between his sense of breathlessness and panic behaviour. He makes it clear that, in this instance, his breathlessness was caused by a lack of oxygen—"no oxygen". P10 used two negative phrases—"I couldn't", "wasn't"—to emphasise the seriousness of his oxygen supply problem:

105 /Something
106 happened to my tank /I couldn't /[h] Wasn't getting [taps table] no
107 oxygen

In the final evaluation phrases P10 restates his understanding of the relationship between breathlessness and panic behaviour: panic behaviour is initiated by an uncontrollable sense of breathlessness, i.e., "when you can't breathe". P10 admits that during these experiences he is afraid. The repetition of the phrase "it's scary" underscores P10's fear. The coda phrase suggests that this sense of emotional vulnerability is something that now occupies his thoughts:

109 /But ah [h] It it it's **it's scary** /It's scary /when you
 110 can't breathe ah [short cough] /It's something to think about

The second account in this trilogy of emotional vulnerability stories further elaborates P10's understanding of the complex relationship between dyspnea and physical and emotional functioning. Although P10 reiterates that he has "learned" of the need to control his emotional response in most situations of respiratory distress—"calm down", this second story also suggests that he recognises that, for him, even minimal physical activity and normal emotional responses to common situations of everyday life can now precipitate or escalate unusual dyspnea. An increase in his usual level of breathlessness can then potentially force a further reduction in physical activity and result in emotional behaviour that is inappropriate:

113 /'cause I /kinda leaned to /[h] calm down when I get excited /I calm
 114 down a bit eh /[h] Like I can't seem to..get excited about anything

Through this second story P10 again makes visible his sense of emotional vulnerability by recounting the events of a recent experience of breathlessness. The orientation phrases indicate that the second story took place in P10's home during a routine visit of the nurse (VON) who was supervising his care in the community:

115 Like ah the VON [*community nurse*] was at the house the other day /[h] I couldn't find
 116 her /her papers [h] [taps table]

The narrative phrases that recount the story events perform both a descriptive and an evaluative function. P10 implies that he became breathless as he unsuccessfully searched for nursing care documents. He also implies through the nurse's voice, that he believed this caregiver recognised his physical distress:

116 /An I start lookin' for those papers
 117 /An the [h] [coughs] /Well she had
 118 to [h] tell me to sit down and be quiet [taps table] /"**Never mind the**
 119 **papers**" /said "**We'll get them the next time**"

The evaluation phrases that surround the narrative clauses, however, emphasise

the complex relationship between routine physical activity, minimal stress, breathlessness and emotional distress. P10's description of his frustration at not being able to find the "papers" along with the minimal physical exertion required to search for them indicate his sense of emotional vulnerability:

117 /I know I was all up in [coughs]
119 /An I was SO..um /how
120 would you say that? /ahm...[-h] T' find I wanted so much to find
121 those papers for her [taps table] /that it got me all upset

P10's sense of frustration (emotional distress) caused by such a seemingly trivial problem necessitated not only stopping all physical activity but also resulted in what P10 intimates was an inappropriate emotional reaction:

123 P10: An I just didn't cry /but [h] it was that close

Further, this story suggests that P10 is emotionally vulnerable. From his perspective, the relationship between dyspnea and emotional functioning was both complex (i.e., breathlessness caused panic and panic caused increased breathlessness and more panic) and circular. That is, breathlessness apparently exacerbated by both emotional feelings such as frustration and minimal physical activity resulted in not only physically incapacitating dyspnea but also disproportionate emotional distress. In addition, on occasion the experience of an emotional response was both a contributing factor in P10's increased respiratory distress and a sign of an impending episode of unmanageable dyspnea.

The final story in the above trilogy powerfully re-addresses the relationship between being "out of oxygen" (dyspnea) and emotional functioning (what I have called emotional vulnerability). In this story P10 implies not only that a lack of oxygen makes him emotionally vulnerable, but more importantly that, on this occasion at least, the first sign of impending acute respiratory distress (that took him by surprise)

a horse". The explanation suggests P10's recognition of a dyspnea-anxiety-dyspnea cycle related to an oxygen deficit:

134 But I was out of oxygen /I didn't know it

P10, through his story implies that he has now learned that not having enough "oxygen" makes him emotionally vulnerable (crying inappropriately). Although he does not understand it, this emotional reaction, associated with dyspnea (caused by a lack of oxygen), is unpredictable and outside of voluntary control.

A last vulnerability story, told near the conclusion of the interview, is presented as a final example of the complex relationship between dyspnea and emotional vulnerability as talked about by this patient.

P10: Emotional Vulnerability Story

If your lungs don't work /your legs won't work

Evaluation:

371 P10: If your lungs don't work /your legs won't work

372 PAT: No they //won't

Abstract/Evaluation:

373 P10: No [h] [-h] [h] but ah /..oh it's hard /[h] I can't stand crowds/

374 [taps table]

Orientation:

374 /I go in--I tried to go at the bas--b' basement of the

375 church an play cards /on a Friday afternoon

Complicating Action:

375 /So I tried to go down

376 there an [h] play cards

Complicating Action/Evaluation:

376 /Oh I got down alright /but the people /You

377 just [h] like this /An nobody smokes though /[h] But the crowd /[h]

378 seems to ah [taps table] /I don't know what it does

Evaluation:

378 /but ah /can't

379 stand crowds

380 PAT: Yeah

Evaluation:

381 P10: I don't know why

Resolution:

381 /So I quit that

Coda/Evaluation:

381 /there don't seem to be any

382 place where I can go t' /[h] t' really relax

In this final story P10 describes his inability to enjoy an afternoon of card playing

375 /So I tried to go down
376 there [*the church basement*] an [h] play cards
378 /but ah /can't
379 stand crowds
381 /So I quit that

371 P10: If your lungs don't work /your legs won't work

In telling this story P10 gives a picture of his complex experience of dyspnea. Albeit not expressed as an emotional response as in the previous story, P10's sense of distress is perhaps best understood as emotional disability:

376 /Oh I got down alright /but the people /You
377 just [h] like this /An nobody smokes though / [h] But the crowd / [h]
378 seems to ah [taps table] /I don't know what it does

381 /there don't seem to be any
382 place where I can go t' / [h] t' really relax

In summary, P10's stories present vivid examples of the complex circular nature of dyspnea and physical and emotional functioning. They also highlight that dyspnea is a subjective and invisible experience. The next case example includes vulnerability stories told by another COPD sufferer. Although the circumstances of the acute exacerbation events and the family structure are not the same, this participant also related vulnerability stories about his experiences of acute exacerbation events.

Case Example #4

P8, a 79 year old retired machinist, was brought to hospital by ambulance on Christmas morning. He had suffered with lung disease for several years; a condition he reluctantly associated with lifelong smoking. This illness had resulted in several emergency hospital admissions, the most serious occurring a year and a half ago. Since that time he had been on continuous home oxygen therapy. P8 lived with his wife and primary family caregiver (CG8.1) in a small wooden frame house. He had an all-purpose workshop in his garage, but was now unable to spend much time there because of his disabling dyspnea.

He had two sons, the youngest (CG8.2), lived in town and assumed caretaking responsibilities for both parents. CG8.2 and his wife visited his parents for approximately half an hour everyday on their way home from work. During dyspneic episodes CG8.2 was frequently called by his mother to make decisions regarding the management of what the parents believed was a respiratory crisis. In the course of my conversation with CG8.2, I learned that P8 and his wife spent much of their day arguing. According to P8's son, the family was concerned that CG8.1 may have been in the early stages of Alzheimer's disease. Nevertheless she continued to assume the primary caregiving responsibilities for her husband. Indeed, during in this acute exacerbation event she had called her son to gain assistance in making the decision about hospitalisation.

When I met P8 he was resting in bed. He was receiving intravenous steroid and antibiotic medications, continuous oxygen therapy, and inhaled bronchodilators. I spoke with P8 at his bedside on the in-patient unit the day after his admission. Although he talked of his experiences of acute dyspnea, he was unable to recall

specific details of the circumstances surrounding this present admission. A later conversation with CG8.2 confirmed that P8 had a memory loss of approximately four hours on the morning he was admitted to hospital. Two vulnerability stories about P8's understanding of his experiences of acute episodes of breathlessness identified in this interview are presented below. The first, told by P8 in response to a direct question regarding the circumstances precipitating his current admission, describes, in part, P8's understanding of the inextricable relationship between physical and emotional functioning and acute respiratory distress. In the second P10 describes his sense of physical disability and vulnerability.

P8: Emotional Vulnerability Story

I I couldn't ah get enough oxygen /enough in

Story Stimulus/Orientation:

20 PAT: So wh' /ah when you said you think your wife had more to do
21 with it /what happened yesterday? /Exactly?

Evaluation:

22 P8: Well I couldn't ah /I I couldn't ah get enough oxygen /enough in
23 ah
24 PAT: Yeah

Abstract:

25 P8: That's the same thing /[h] that's you get the same feeling /You're
26 under under water

Complicating Action/Generic Story

26 /You dive under water /[h] and you..you stay
27 there a little longer than you're suppose to stay /[h] An you c' when
28 you're comin' up for breath 'n

Resolution:

28 /[h] An ah you just just you know /you
29 just starving for [h] for air eh

Evaluation:

29 /That's the way you feel

Coda/Evaluation:

30 PAT: And that's how you felt yesterday?

31 P8: That's the way I felt yesterday /I just couldn't ah /..You know it
32 /I just couldn't couldn't get get enough oxygen in in

Although the interview question initiating this story asked about what happened prior to this hospital admission—"exactly", the story P8 tells is a general description of what it usually "feels" like when he is short of breath. Prior to this story, P8 had indicated, as suggested in the interview question, that his wife had called for help

when he became short of breath the previous morning. As noted above, P8 did not have a clear memory of the specific circumstances of this acute exacerbation event. This memory gap may, in part, account for his use of a generic story describing what for him was a typical experience of unusual dyspnea rather than telling of the circumstances of this acute episode.

In the narrative phrases of this generic story P8 employs a metaphor from everyday life to communicate the abstract concept of intractable dyspnea: i.e., diving under water when swimming, staying too long, and the feelings such a circumstance generates—"starving for air". The narrative phrases imply that shortness of breath is usually the result of physical activity: i.e., in the context of the metaphor, staying under water too long. The repetition of the particle *just* emphasises the emotional distress of the situation (Lee, 1989):

26 /You dive under water /[h] and you..you stay
 27 there a little longer than you're suppose to stay /[h] An you c' when
 28 you're comin' up for breath 'n/[h] An ah you **just just** you know /you
 29 **just** starving for [h] for air eh

The narrative phrases are framed by similar evaluation clauses that extend the intent of the swimming metaphor. When underwater "a little longer than you're suppose to" it is impossible to get a desperately needed breath—"you just starving for [h] for air". In the evaluation segments P8 implies that although he may not be able to remember the actual events he can remember the feeling: i.e., when he was short of breath on this occasion he "couldn't get enough oxygen"—he was "just starving for air". His repetition of the evaluation phrases, use of negative clauses, and repetition of the word intensifier *just*, as highlighted below, emphasise the dyspneic experience he is trying to communicate. At the conclusion of the story the addition of the word, *just*, further underscores his sense of usual distress during an acute exacerbation event

(Lee, 1989):

22 P8: Well I couldn't ah /I I couldn't ah get enough oxygen /enough in
23 ah

31 P8: /I just couldn't ah /.. You know it
32 /I just couldn't couldn't get get enough oxygen in in

Although the narrative phrases, as suggested above, link intractable dyspnea to physical activity, P8's metaphor clearly implies a situation of emotional and physical distress. His use of the imagery of being underwater and "starving for air" creates a sense of recognisable emotional vulnerability:

29 /That's the way you feel

In summary, P8 makes his experience of intractable dyspnea understandable to the hearer by the use of a metaphor. In a second story P8 contrasts his childhood experience of unbounded physical energy with his present physical disability. This story is presented as another example of P8's attempt to convey his daily experience of incapacitating dyspnea. In the following story he portrays the subjective experience of breathlessness as acquired physical disability and physical vulnerability.

P8: Physical Vulnerability Story

An we used to run

Abstract:

81 P8: Oh I /wh' when I was a youngster /I used to [h] /I did
82 everything you know like /Participated in sport /I even ah like I was
83 /...I came I come /I'm a farm boy eh

84 PAT: Yeah

Orientation:

85 P8: And ah neighbour of mine /we used to just /for practice /[h] This
86 /There was a store /about three miles down /and we'd both **run** there

Complicating Action:

87 /Say "Let's let's **run**" /"See if" [h] /"How how..let's ah that" /Ah you
88 know /You can maintain that /[h] ah **running** eh

89 PAT: Umhum

90 P8: An we used to **run** to that /Have a /have a /buy c' candy or
91 chocolate bar or [*cigarettes*]

Resolution:

91 /Do the same thing /**run** back eh

Evaluation:

91 /you know

92 Anything to to... /to s' or anything to do like eh

93 PAT: Yeah

94 P8: Because ah /well farming was always some /oh some profession
 95 eh
 96 PAT: Yeah
 97 P8: So...so now [clears throat]
 98 PAT: But now //running is not?
 99 P8: Eh] /oh I just just thinkin' about that now /I NEVER /[h] well I
 100 Ah if I **walk** a block that that plays me right out /I gotta stop /[h] I
 101 gotta take my breath back you know
 102 PAT: Yeah
 103 P8: Even **standing up** /[h] bothers me /oh knock the hell out
 Evaluation:
 103 /[h] it
 104 bugs the hell out of you

Again, although P8 cannot recall the circumstances surrounding his current hospitalisation, as highlighted above, he tells a story of physical functioning which contrasts what it is like to be unable to function because of shortness of breath. The narrative phrases of this childhood story describe a memory of seemingly limitless physical activity:

87 /Say "Let's let's **run**" /"See if" [h] /"How how...let's ah that" /Ah you
 88 know /You can maintain that /[h] ah **running** eh

The evaluation phrases juxtapose P8's memory of youthful vigour with the acquired physical vulnerability of his present circumstances, the consequences of his chronic lung disease. Now even limited physical activity—"walking", "standing"—is not possible without respiratory distress:

99 P8: Eh] /oh I just just thinkin' about that now/I NEVER /[h] well I
 100 Ah if I **walk** a block that that plays me right out /I gotta stop /[h] I
 101 gotta take my breath back you know
 102 PAT: Yeah
 103 P8: Even **standing up** /[h] bothers me

P8's story again portrays in a readily graspable way the breathlessness which has rendered him physically vulnerable in even the most ordinary of circumstances: i.e., "if I walk a block", "even standing up". In the evaluation phrases, by concluding the story with a confession that his physical incapacity has an emotional aspect, P8 also conveys that there is a relationship between breathlessness and emotional functioning.

He experiences a physical response—"knocks the hell"—and an emotional response—"bugs the hell". Repetition of the word "hell" emphasises that both aspects of the experience are potent and negative:

103 P8: /oh knock the hell out /[h] it
104 bugs the hell out of you

Both of the above stories clearly illustrate the complex relationship between physical functioning and the experience of incapacitating breathlessness.

Summary

The preceding patient and family caregiver stories illustrated the physical and emotional vulnerability experienced by members of two family units. Although the circumstances of the above breathless episodes were from specific participant interviews, they are examples of the story structure and content of physical and emotional vulnerability stories identified in all the patient and family caregiver interviews. The narrative phrases of these stories revealed the complex and circular relationship between physical activity, emotional behaviour and intractable breathlessness as understood by these participants. The underlying experience of these patients was shortness of breath, an experience that was essentially subjective and invisible. These stories, as told by patients and their family caregivers, made visible the subjective nature of dyspnea as well as the physical and emotional vulnerability experienced by these patients.

CHAPTER 8

CAUSES OF ILLNESS STORIES

"Sure I've smoked all my life /but I also put in 37 years at /the mine"

During the study interviews, I routinely asked patients and family caregivers about what happened this time when the patient became sick. In addition I asked if they knew what made it necessary for them to come to the hospital. I also frequently inquired about how the patient had originally gotten their lung disease. My requests for information about the causes of acute and long-term illness resulted in two groups of stories: i.e., stories about the causes of COPD and stories describing the circumstances related to acute exacerbation events. In response to how or why the patient had developed chronic lung disease, patients and family caregivers repeatedly talked about the patients' smoking history or their exposure to environmental or industrial pollution or both (see Table 6, Appendix A). In the stories involving the circumstances precipitating or preceding an acute exacerbation event, participants were less precise. They talked of things such as infections and weather changes as sometimes either coinciding with or actually causing acute respiratory distress that necessitated admission to hospital. They also spoke of the usual circumstances in the early stages of an acute exacerbation event.

A closer examination of both of these groups of stories demonstrated that for many participants the description of a cause of either an acute dyspneic episode or the acquisition of their chronic lung disease was not a straightforward task, and generally involved the telling of complex stories. For example, although most of the patients had

a long-standing smoking history, they did not always simply attribute their illness to this habit. More often they offered at least one alternative causal explanation detailing the circumstances in which they had lived and worked. It was also apparent that the stories told by these participants explaining the cause(s) of their chronic lung disease could be understood more fully by taking into account the context of their telling.

As already indicated, these patients and family caregivers were usually individuals with an extended history of living with chronic lung disease. Because of episodes of acute respiratory distress, they had experienced a number of emergency hospital admissions and hence were aware of the association between smoking and the development of COPD accepted by health care professionals. In addition, they lived in a mining community with a long-standing legacy/reputation of air pollution and generally shared the lay community's understanding that chronic air pollution had also contributed to the development of their lung disease. The participants told these stories, in part, to present the cause of the patients' lung disease as something related to their life experience, but outside of the patients' control. These stories demonstrated that these participants saw the patient as a victim of circumstance: i.e., a miner who had been required to work in a polluted environment, a resident of a mining community known for its poor air quality, or a smoker who acquired the habit at a time when the hazards of smoking were unknown.

When talking of acute exacerbation events, patients and family caregivers also spoke of possible precursors of acute exacerbation events. Analysis of several of these stories suggested, however, that often participants did not always know what made the patient acutely dyspneic. Nevertheless, these participants told stories indicating that they did know when the patient was acutely ill, and often used specific changes in

appearance and behaviour as indicators of impending respiratory distress serious enough to necessitate emergency hospitalisation. The stories describing the circumstances surrounding acute exacerbation events functioned to highlight both the impreciseness of the causes of acute episodes and the patient-specific nature of the behaviours that were used by participants as they determined when the patient's breathing was deteriorating indicating the beginning of an acute exacerbation event.

In the following section I will consider in detail the structure, content, and function of the stories describing the patients' and family caregivers' attempts to make sense of both the causes of their chronic and acute illness and the circumstances of acute exacerbation events. In this chapter my initial purpose is to further demonstrate the complexity of the participants' interpretation of the causes of both the patients' chronic lung disease and the circumstances surrounding acute exacerbation events that necessitate emergency hospitalisation. The process is also intended to communicate how analysis of these stories within the context of their telling contributed to the understanding of acute exacerbation events as understood by the patients and their family caregivers.

Causes of Chronic Lung Disease Stories: Structure and Content

The stories told by patients and family caregivers about the causes of the patient's chronic illness frequently took the form of generic stories and were presented as explanations from the participants' point of view of how the patient had developed chronic lung disease. It was common for the participants to tell their stories with layers of explanation involving either the repetition of sections within the story or the inclusion of more than one story about the same event to strengthen their explanatory

presentation. An important similarity in the structure of these explanatory generic stories that assisted in the accomplishment of this task was their inclusion of extended orientation sections and narrative phrases that also performed an orientation function.

Both these segments or phrases consistently presented detailed descriptions of the situation in which the patient lived or worked. In addition, although the generic stories did not describe a particular event, they usually included orientation phrases that placed the story within the context of a specific extended time frame. Participants did not describe unique or abnormal events, but rather talked of common personal or environmental circumstances. Similarities among stories were also noted in the events predisposing the patient to chronic illness described by the narrative phrases. As noted above, the circumstances that were most often described included references to smoking behaviour and descriptions of some form of poor air quality, either environmental or industrial pollution.

Smoking and Poor Air Quality Stories

The following story segments from patient and family caregiver interviews are presented, in part, to demonstrate these outlined structural and content similarities. The examples also illustrate the storytellers' use of detailed orientation phrases, contrast structures, rhetorical devices, and references to time in the framing of their stories. The narrative events generally centered on the two causes that participants most frequently spoke of as potentially being related to the patient's development of chronic lung disease, i.e., smoking and pollution.

In the following story segment, P8, a retired mechanic with end-stage lung disease, describes in detail about his experience of purchasing and smoking cigarettes as a

youngster. The orientation phrases indicate that this man began to smoke seventy years ago at a time when individuals were unlikely to have recognised the inherent risks of such behaviour. Presentation of his smoking history in the form of a story about a child reinforces the innocence of his behaviour:

Causes of Chronic Lung Disease Story

Have a cigarette of course eh

P8:

- 424 PAT: How did you get your lung disease?
 429 P8: When we [*my friend and I*] used to
 430 run to /[h] the store
 431 PAT: Yeah
 432 P8: Three miles away /that's what we run for [h]
 433 PAT: Cigarettes
 434 P8: Cigarettes [laughs] [coughs] /used to [h] /In those days we used
 435 to buy five cigarettes you know
 436 PAT: Yeah
 437 P8: [h] Five in a package /an ah we were /Well [h] we run there
 438 /Buy them our ci' /He'd buy a pack and I'd buy one /They were five
 439 cents for five /[h] I forget if it was a five cents a package or
 440 somethin' a cigarette /or a cent a cigarette anyway /[h] And ah
 441 like..we'd [h] run back /Ah run to the store but we /We walked back
 442 /Sit down an talk /Have a cigarette of course eh

The irony of the seemingly innocuous actions of childhood are captured in the implicit contrast structure of P8's story: i.e., the limitless mobility of his youth—"run[ning] to the store", a distance of "three miles", to purchase cigarettes—with his present inability to go anywhere without continuous supplemental oxygen; and the relatively inexpensive price of pleasure when P8 was a child—"a cent a cigarette"—with the eventual cost of smoking to his health in old age.

In the next two story excerpts patients describe circumstances of environmental pollution as instrumental in the development of their chronic lung disease. These examples illustrate the participants' use of detailed generic phrases in their explanations of these causes of chronic lung disease. In the first excerpt, presented more completely at the conclusion of the chapter, P5, a retired miner with a long-

standing history of COPD, describes a specific interaction with a hotel manager. Through his story P5 proposes Legionnaire's disease as a possible explanation for the development of his lung disease. In his explanation he includes orientation information (about the air-conditioner, its function and maintenance status) that is essential if his explanation is to be understood. He implies that he has inadvertently been exposed to a harmful substance and his storytelling allowed me to infer that the presence of "white fuzzy stuff" in an air-conditioner could conceivably precipitate chronic lung disease:

Causes of Chronic Lung Disease Story

I was thinkin' about that Legionnaire's disease eh

P5:

702 P5: And one time I went there /[swallow] an I started-I was thinkin'
 703 about that Legionnaire's disease eh
 704 PAT: Yeah
 705 P5: ...An I asked the..house manager [*of the hotel*] /I says "I'd like the filters
 706 changed on my" /'cause they've got air-conditioning /combined air-
 707 conditioning and heating units /so the guy come up /[swallow] an
 708 when he took the filter out /it was full of the sort of a white /ah
 709 fuzzy stuff you know

In this second example P7, a 70 year old housewife and chronic smoker, contrasts the air quality of her childhood village in Eastern Europe with that of the mining community where she spent most of her adult life. The presentation of her story required that I infer that air quality was the key factor responsible for the development of her end-stage COPD—"but I cannot breathe after the year I come here":

Causes of Chronic Lung Disease Story

Was fresh air

P7:

92 P7: Was fresh air /it's of fresh air /an' where I come /the village
 [Eastern Europe]
 93 /There is a mountain forest /with lots of water
 94 PAT: Pardon me
 95 P7: Lots of water
 96 PAT: Lots of water
 97 P7: Yeah an' I can
 98 PAT: The humidity eh

99 P7: Breathe that //yeah
 100 PAT: Yeah]
 101 P7: But I cannot breathe after the year I come here
 [mining town]

Industrial pollution was also described by several participants when they talked of the development of their chronic lung disease. The following examples illustrate three patient's use of detailed orientation segments to provide necessary information for me (a non-miner) to understand and subsequently be persuaded by their causal explanations. For example, P5, a retired miner, told a story of a work environment that was so polluted with chemicals that he was blinded. P10, also a retired miner, talked of working with chemicals and spoke in detail of inhaling the "fumes" that were created by these compounds. P11, a retired electric welder, described the "fumes" and "dust" which contributed to his end-stage disease. In two of the excerpts (P10, P11) the patients structured their story within an extended time frame emphasising their prolonged exposure to these harmful agents. As highlighted below, the use by these participants of rhetorical devices such as lists—"I was exposed to SO₂ /NH₃ /NH₄"—word repetition—"fumes"—and intensifiers—"very har' heavy /[h] very hard"—strengthened the presentation of their stories of exposure to industrial pollution as a credible cause of their chronic lung disease:

P5:
 528 PAT: That's OK /what do you think has led you to have this lung
 529 disease?
 533 P5: And ah /...all of those years [*working for a mining company*]
 /I was exposed to SO₂ /NH₃ /NH₄
 534 /NH₄2S /An I could go on with the chemicals /And ah..the SO₂ that
 535 we were in /...In order to be able to go from place to the other
 536 sometimes /all you could do was crack an eye lid /'cause you
 537 couldn't keep you eyes open /It was that strong

P10:
 398 PAT: And what do you think causes it [*COPD*]? /for you?
 399 P10: [h] [-h]..Underground mining /Dust /nickel dust /That's what
 400 caused it I'm sure /[h] An where I was workin' /I was 15 years [h] in
 401 the same job /Was all kinds of fumes /[hh] Now I don't know if you
 402 know about [h] tailings fill

403 PAT: No
 404 P10: Eh /it's ah [h] wast e/from the rock that's [h] crushed and
 405 mixed with ah water /And it's all piped /It's the waste /and it's all
 406 piped un' [h] underground /It leaves it leaves [taps table] surface
 407 /It's cold gets down underground where it's warm /[h] and it runs in
 408 there like /[h] [taps table] ah water /Like water and sand mixed /[h]
 409 Through a three inch pipe /[h] [-h] An you're filling up these holes
 410 /that's mined out /...An you're standin' behind and you gotta watch
 411 this /[h] That nothin' goes--that nothin' happens /And the **fumes** come
 412 with that /[h] An it's just ah [h] [coughs] I don't know the name of
 413 the /[h] of the ah....stuff that they put into /to mix it ah [h]
 414 PAT: Yeah
 415 P10: Ah there's four or five different kinds of [h] /of medical
 416 things /ah /medical they put in there or something like that?
 417 PAT: Of chemical?
 418 P10: Chemicals /that they put in there to dissolve [taps table] this
 419 /[h] An an ah the **fumes** of that that I've been inhaling /[h] Was
 420 'haling those **fume** for [h] for 15 years /[h] [-hh]

P11:
 76 PAT: OK so /in those days you'd get worse short of breath with
 77 dust or cold or?
 78 P11: **Cement dust** was very bad /[h] **Diesel smoke**
 79 underground was very bad /[h] And I was an electric welder for /[h]
 80 for almost 20 or 25 years /[h] And the **dust** off [h] electric welder
 81 /[h] is very har' heavy /[h] and very hard to take

Causes of Chronic Lung Disease Story: Meanings and Function

Before proceeding with a description of the function of these stories it is necessary to examine the reasons presented by the participants for telling stories about how the patient developed their chronic illness. It is apparent that these stories were told within the context of the Canadian health care system and a specific mining community. A patient living with COPD characterised by acute exacerbation events necessitating hospitalisation in Canada would confront within the health care system the prevailing medical perspective regarding the aetiology of COPD. During the course of their care, these patients and their family caregivers would have been informed of the recognised association between the development of chronic lung disease and a history of smoking. In addition, it is reasonable to assume that during every subsequent acute exacerbation event they would have been reminded again of the consequences of such smoking

behaviour.

The belief that smoking was a cause of chronic lung disease was presented in many participants' stories. In a number of evaluation phrases, as demonstrated above, smoking behaviour was also clearly linked with the physician's perspective of why patients developed COPD. As the following examples demonstrate, some patients and family caregivers appeared to acknowledge either that a prolonged history of smoking was the essential precursor for the development of the patient's chronic lung disease or that it was the reason most doctors gave as being responsible for the development of COPD:

P8:

426 PAT: How did you get lung disease? /Do you have any?

427 P8: Oh I smokin' for a long time

CG7.1:

349 CG7.1: [coughs] [*P7 stopped smoking 3 years ago*] but was too late

350 PAT: Yeah //well

351 CG7.1: Doctors] doctor told me says /"90 percent is from

352 /cigarette" /...Yeah

CG11.1

277 CG11.1: He was a heavier heavy

278 smoker /and I think that a lot of that /you know /a lot of it had to

279 do with that

Alternative factors were also suggested as the causes for the development of the patients' underlying chronic disease process. These ideas can be associated, at least in part, with living in this Northern Ontario mining community. The area, a region known for its mining industry, has a long history of industrial pollution and the evaluation phrases of several stories demonstrated that industrial pollution was accepted as a probable causal factor of chronic lung disease by a number of patients and family caregivers. In some stories these participants simply stated that this kind of pollution precipitated the patient's lung disease:

P10:

399 P10: [h] [-h]..Underground mining /dust /nickel dust /that's what
400 caused it /I'm sure

In others the participants used contrast structure within the story itself to illustrate that the circumstances in which they used to work—"in those [them] days"—were truly unsafe. The more recent introduction of protective face gear ("masks") or ventilation systems ("bats") confirmed their assessment of their former working environment:

P10:

420 P10: /'Course in those
421 days was no /no mask no ah /You went down there done your job
422 /If you couldn't do your job /Well somebody else take your place

P11:

81 P11: /[h] An in them
82 days /[h] we didn't have ah /[h] well ventilated rooms to work in
83 /No bats [*ventilation ducts*] over you head an everything /[h]
It wasn't like it is today

However, the participants' understanding of the causal factors did not always present as an either/or perspective. It was apparent that for several patients and family caregivers the cause of chronic lung disease was something other than simply having been (being) a smoker or having worked or lived in a polluted environment. Moreover, these stories sometimes demonstrated that a tension existed around what the patient and their family caregiver(s) believed had contributed to the development of the patient's chronic lung disease. For example, although I identified that eleven of the twelve patients in the study were smokers, not all patients spoke of their smoking history when talking of the underlying causes of their chronic disease.

Some patients, in contrast to their family caregivers or the physician, actually rejected the notion of smoking as a legitimate causal factor. Others patients and family caregivers acknowledged the patient's smoking behaviour, but minimised its contribution to long-term illness and presented alternative environmental causes for the development of chronic lung disease. The evaluation components of a number of

stories clearly claimed that the patients (even those with a smoking history) had lived or worked in an unsafe environment—an environment which had unwittingly damaged their lungs and ultimately left them chronically ill. Their stories inevitably functioned to portray the patients as victims of their living or working circumstances.

The following excerpts from two family units illustrate the tensions between possible explanations given by both patients and family caregivers. Although more complete narrative segments will be presented as example stories later in the chapter, the following excerpts from P5's and CG5.2's interviews are instances specifically demonstrating the conflict between worksite pollution and smoking as the primary cause of this patient's chronic disease and the patient as victim:

P5:

530 P5: Well...that /the doc-you ask every doctor /he'll say smoking
531 /Sure I've smoked all my life /but I also put in 37 years at the mine

CG5.2:

161 CG5.2: /But it's I mean it's s'you know sixty years of smoking /An
162 smoking VERY HEAVILY for fifty of 'em anyway
163 PAT: Um
164 CG5.2: An I guess I sure the mine didn't help /you know /Working in
165 the mine /He was never underground /But I mean they were working
166 in all kinds of gases /An you know noxious noxious fumes an what

The second example underscores the conflict between smoking and environmental pollution. From the following orientation phrases of P7's story, it is reasonable to assume that she believed that I, as a resident of the area, would have understood the comparison she was making:

P7:

89 P7: The doctor [h] than' it was from smoking /*[But I think]* the smoky place you
90 know *[the community's level of air pollution]*

CG7.1:

291 CG7.1: She not believe is from //cigarette
292 PAT: Smoking] //She doesn't believe that
293 CG7.1: Oh no] /no no /She says "How come somebody live 100
294 years /and ah aah smoke" /She says "No that's from the air
295 /pollution"

In summary, it was clear that these participants told stories to communicate their understanding of the causes of the patient's chronic lung disease from within the context of their experience; these individuals had interacted with the health care system as patients or family caregivers managing chronic lung disease characterised by acute exacerbation events. It is apparent that several of these stories, as alternative causal explanations, are best understood within this context. Analysis of these accounts, however, regardless of the context, suggested that these often complex stories directly or indirectly functioned to portray patients as victims of their circumstances: i.e., a miner who had been required to work in a polluted environment, a resident of a mining community known for its poor air quality, and a smoker who acquired the habit at a time when the hazards of smoking were unknown.

Causes of Acute Exacerbation Event Stories: Patient and Family Caregiver Stories

In another group of stories, patients and family caregivers, again usually in response to a direct question, spoke of the causes of acute exacerbation events and of the patient behaviours associated with these acute episodes. Like the stories telling of the causes of COPD discussed above, these accounts were most often presented as generic stories outlining the behaviour or events surrounding acute events in general. When the participants told an event-specific story to describe circumstances precipitating an acute exacerbation episode, it was not unusual for the orientation and evaluation phrases of these stories to be presented as generic stories within the story itself; that is, they talked about this particular acute incident within the context of what usually happened.

In addition to these structural similarities, several analogous content elements were

also identified across these stories: i.e., accounts of actual factors precipitating an acute exacerbation episode such as infection and poor air quality; and descriptions of signs or circumstances of impending intractable dyspnea such as skin colour changes, loss of appetite, and decreased activity levels. In the following section I will examine these stories more closely in relation to their structure, content, and function. The discussion will demonstrate that participants stated that they knew when the patient was acutely ill. Their stories will also illustrate that these participants, as suggested by Strauss and colleagues (1984), consistently monitored the patient's behaviour to guard against the occurrence of acute exacerbation events.

Causes of Acute Exacerbation Events

A minor respiratory infection was the most common cause that patients and family caregivers associated with the patient's acute episodes of breathlessness. As the following excerpts show, an infection was typically talked of either as something that came on very quickly or as something that lingered on for an extended period of time. As highlighted below, the infection itself was not serious, and was usually described as the common cold. It is apparent that these participants monitored the patient when they developed this minimal kind of infection:

CG4.1

- 202 PAT: Do you have any idea what causes this shortness of breath?
 203 CG4.1: Aaah right now it's de spit /it's de cold
 204 PAT: It's the cold
 205 CG4.1: The cold
 206 PAT: If he get's a cold /you know he's going to get short of breath
 207 CG4.1: Oh yeah oh yeah /'cause he gets a cold /He got ah /he got
 208 ah /he got all dat stuff inside you there

P6:

- 208 /[[hh] I went to the /..I don't I've when I
 209 had that first cold /[[hh] I went to emergency here

CG7.1:

109 CG7.1: [coughs] /No she didn't get no cold this time /once before
 110 she get cold

CG9.1:

19 CG9.1: She had a cold for about /couple of
 20 weeks bef' prior to Friday morning /an then at 8:30 she came

In a second group of stories patients and family caregivers spoke of acute events in relation to the even less precise cause of poor air quality. In the following excerpts from several interviews the participants' narrative phrases described either changing weather conditions or the air quality in the patient's home. In the first example a patient talked of breathing more easily when he went outside into the "fresh air". In the second the family caregiver described weather changes as a potential reason for the patient's development of an acute event. Family caregivers in the final two examples described indoor air quality in relation to the possible precipitation of an acute episode. In each example the participant included extended orientation information within the narrative phrases. Inclusion of this information clearly set the scene of each story. Use of direct quotations and changes in the volume of the conversations emphasised the participants' claim that these factors were responsible for the patient's acute illness:

P4:

164 P4: Yeah well [-h] I call my my son
 165 PAT: Uhuh
 166 At three o'clock in the morning I said [-h]
 167 I said "Take a cab [-h] /Come get my car an you'll ah
 168 bring me at th'hospital" /[-h] An he d' do it /An in that time I go very
 169 slowly /Take elevator /[-h] Go downstairs and I go at my car /[-h]
 170 An I wake wait on my car /[-h] for the cab you know /An I'm in fresh
 171 air [*instead of the apartment*] /and I'm coming good /I didn't cough

CG12.1:

23 CG12.1: As as soon as de weader turn kind of ah /mis' misty like
 24 you know /like damp den I d' /it seemed to bring it it on him

CG5.1:

605 CG5.1: He's smoking //at home
 606 PAT: Yeah
 607 CG5.1: And he's still smoking /And ah where he'll say "Oh yeah /NO

608 WONDER I CAN'T BREATH /IT'S THAT-THERE'S A DAMN
 609 INFECTION IN THERE" /Or or ah "YOU KNOW WHAT IT IS?
 610 /THE STALE AIR IN THIS HOUSE IS WHY I CAN'T BREATHE"
 611 /So he goes out and he-an I bought him like a five hundred dollar
 612 /ini'you know air you know /Clean the air like three times an hour
 613 an all /the-one of these units

CG5.2:

705 CG5.2: /Like you walk into his home /...and it's so stale in there
 706 //He gets absolutely no fresh air whatsoever /None /And it so stale in
 707 there /And it's so..dry /An there's gotta be so many bizillion smoke
 708 particles floatin' around in there /'Cause like /like I say he sits and he
 709 smokes /An th'the door can go /you know /a couple of days without
 710 being opened /That's the only fresh air he gets EVER

Signs of Acute Exacerbation Events

Not uncommonly, however, participants did not clearly identify specific events or circumstances that regularly preceded or precipitated acute exacerbation episodes. Hence, in the narrative phrases of some stories, patients and family caregivers, instead of describing particular precipitating causes of acute episodes, rather talked of specific behavioral changes or signs of what "usually" happened in the early stages of an acute exacerbation event. Although these participants did not directly describe specific causes in their accounts of acute illness, they did recognise and talk of a variety of patient-specific signs indicating that an individual was becoming acutely ill. For example, as highlighted in the following three excerpts, the participants stated or implied that for them there was an association between changes in the colour and amount of their sputum (a sign), most probably caused by an underlying infection (or "something out there"), and impending unmanageable dyspnea:

P4:

113 P4: Well] [-h] at t' morning /when I woke up /I I cough eh [-h] /an
 114 ah big chunk n' yellow /An **when it's green..y'** you start
 115 Pat: To worry
 116 P4: Yeah /y' you start ah [-h] ah infection **when it's green**

CG10.2:

11 CG10.2: /He was short of breath
 12 /and he had **extra phlegm** in his lungs that /he didn't have when he
 13 left /So something /something out there made him sick

P12:

244 P12: But here /I don't spit like /[h] An at home /when I take dem in
 245 the morning dere /[h] Well I got a bag beside my chair because /[h] I
 246 spit about every five or ten minutes 'n /[h] [-h] [h]
 247 PAT: But what causes that /you don't know eh?
 248 P12: I don't know /It's all green stuff that comes out 'n
 249 PAT: All the time green stuff?
 250 P12: Yeah /just Dr. _____ says to me /says [h] "**If it's brown** or
 251 something like dat dere" [h]

Participants, also talked of other patient-specific markers of increasing respiratory distress. These included such signs as skin colour changes, loss of appetite, panic behaviour, a decrease in activity levels, and shortness of breath. In the generic stories from which the following excerpts were taken it was apparent that these participants were describing the usual early signs of an acute exacerbation event. It is apparent that these somewhat imprecise signs were identified as markers of breathlessness that the participants were now able to identify in advance of seeking help in the management of an acute exacerbation event. As highlighted in the following excerpts from a number of stories, participants' use of word intensifiers—"very", "just", "big"—phrase repetition—"you can hear him"—and direct quotations emphasised the specific nature of the signs of the patient's acute distress:

CG5.1:

32 CG5.1: His [P5] breathing an he's **very very** /get's **very palsied** [bangs
 33 table] /So ah..he' well I mean /he **just** looks /Well he looks like hell
 34 /you know /It [bangs the table] is the bottom line /An **very blue** and
 35 grey looking

CG5.2:

72 CG5.2: /But ah
 73 his colour is **very bad** /He's always a like ah pasty grey colour /you
 74 know /Kind of a **very sickly colour** /an he get's ah /.H'they well we
 75 call 'em **Fred Flintstone feet** /He get's **big /fat** /almost like **big club**
 76 **feet**

CG12.2:

309 CG12.1: /But you can tell when his his appetite starts going [taps
 310 table] down /He his colour is not ah good /And when he doesn't

311 wanna play cards /He just sits there and he /He's looking for his wind
 312 /and you can hear him
 313 PAT: Breathing
 314 CG12.2: You can hear him breathing

P9:

35 P9: /you feel dat coming /You know an ah /the day before
 36 /..start to be short of breath /..If I move /it's worse /'n

CG10.2:

48 CG10.2: /You could tell that
 49 he wasn't feeling well /Um /he has a hard time to motivate /To move
 50 himself around /He doesn't like to get up /Do this /Do that /OK 'cause
 51 he has /he's s' short on breath then

P12:

63 P12: [h] An
 64 Sunday I watch a mass at 10 o'clock /[h] An after that I watch ah
 65 /[h] An she said--ah I said /"I'm [h] I'm not hungry" /"I'm gonna
 66 have soup [h] an toast" /And ah [h] in the afternoon there I got
 67 shaky

Although the above excerpts describe the usual early stages of an acute dyspneic event, the focus of the accounts was not on the patient's breathlessness. Through their stories these participants implied that patients as well as their caregivers used other signs (in combination with a sense of increasing breathlessness) when determining that the patient was actually becoming acutely ill. The following excerpts from two patient interviews illustrate that the participants, for example, viewed the need to change their medication routine as an actual sign of impending unmanageable dyspnea. It would appear that in the early stages of an acute episode the patient's sense of increasing breathlessness alone was not a clear indicator that an acute event was beginning. In these examples the patients determined that they were in the midst of an acute exacerbation event when their self-help strategies were ineffectual in managing their increased sense of breathlessness:

P5:

133 P5 /I went down to four
 [medication inhalations using my compressor] /an then I went
 134 back to puffers /and ah [h] at last there I was every three hours /an
 135 I could barely make it /on three hours so /I said "Hey this is /gone far
 136 enough" /so I come back here [to the hospital]

P6:

65 P6: / [h] like even the machine then doesn't
66 seem to help /you know /like my ventila' my compressor / [hh] I
67 don't have oxygen at home /I don't need it /my oxygen level is OK
68 / [hh] but when I feel that even that is not working /you know / [hh]
69 an I'm in a cold sweat and everything

Causes of Acute Exacerbation Event Stories: Meanings and Function

Three main reasons for telling stories about the circumstances preceding or precipitating the events related to acute exacerbation events were identified in the patients' and family caregivers' accounts. These included showing that the participants knew when the patient was acutely ill, indicating the most common causes of acute exacerbation events, and describing the behaviours associated with the early stages of acute exacerbation episodes. However, the essential function of these stories was that they acknowledged the imprecise but patient-specific nature of the patient's and family caregiver's knowledge of the reasons for acute episodes and the events characteristic of the beginning of acute illness.

The following narrative excerpts demonstrate that patients and family caregivers alike stated that they "just knew"—"I just seemed to sense it", "he knows", "you know", "I can feel it"—that the patient was acutely ill when they saw particular behavioural changes or the patient felt a certain way. In these evaluations phrases the participants frequently appealed to experience to enhance the strength of their claim:

P5:

138 P5 ..I just seem to sense it /because it's happened to me..oh six
139 or seven times now

CG5.1:

19 CG5.1: Ah well this time /i'it's usually a a build-up over a couple of
20 days /He [P5] gets when I go "Oh dad you're not looking too well"

CG5.2:

967 CG5.2: he [P5] can feel it /he can
970 /he knows when he has to come
971 in /and I'm assuming it's the light headedness or whatever

CG5.2:

967 CG5.2: /like this last time /you know
968 with his /with his his blood gases being so off /he knew /and he kept
969 saying that too /he said "See I knew there was some' /I knew I was"
970 you know /"I knew I had to come in"

P9:

35 P9: Yeah /you feel dat coming /You know an ah /The day before
36 /..start to be short of breath /..If I move /it's worse /'n

P11:

109 P11: Oh I know /[h] if you've got a sliver in your finger /you know
110 there's something wrong [h]
111 PAT: Got a sliver /yeah
112 P11: [h] Yeah] /Well /that's the same as me when I get plugged now
113 /[h] [-h] I can tell if my lungs start to plug up in the bottom
114 /because [h] I can't take a deep breath

P12:

62 P12: [h] Seems to me that ah /I can feel it coming

CG12.2:

301 CG12.2: Yeah /I know /he [P12] feels ah /there more days worse than
302 others /Ah it seems that ah /...you see when he's ah /when he's up
303 /An then when he deteriorating /I notice a difference in him /'cause I
304 know when he's gonna start getting sick

The evaluation phrases of a number of the stories reinforced the narrative elements of the stories by again indicating that these participants did, on occasion, associate acute exacerbation events with some form of infection or change in the weather. It was apparent that the point of their story was to demonstrate their recognition of the relationship between this circumstance or sign and an acute exacerbation event. Again, the patients and family caregivers referred to their past experience with acute exacerbation events adding a sense of credibility to their claim. The relationship between the signs of acute illness and the experience of acute illness, as highlighted below, however, were characterised as situations that were somewhat imprecise. The frequent use of phrases such as "must have", "I think in my case", "it seem[s]ed", and words such as "usually" and "something" when referring to both infection and changes

in the weather, reinforced this sense of imprecision:

P5:

594 P5:But ah lately I've been bringing up a lot more [*sputum*] with this /so it
595 **must have been** a bug again

CG5.2:

159 CG5.2: He um he always attributes it to um /"Oh I **must have** a little
160 infection /I **must have** a little affection" /That's why he's feeling
161 worse

P6:

215 P6: /you like I [hh] I **think in my case** it's just an accumulation /When
216 the weather changes /It it's damp /'n if it's this /'n if it's that 'n/[hhh]
217 It does that to me //[hh] [-hh]

CG10.2:

8 CG10.2: When he goes to the hospital /it's
9 **usually** because of an infection or /**something's** come on /He's
10 catching a cold /or he's getting **something**

CG11.1:

153 CG11.1: /He he he's never really well in the winter time /I don't
154 know why /What it is /Why--whether it's the difference in the cold or
155 /But I mean he stays in mostly /You wouldn't think it would bother
156 him that much but /**It seems** the winters are the hardest on him

CG12.1:

23 CG12.1: As as soon as de weader turn kind of ah /mis' misty like
24 you know /Like damp den I d' /it **seemed** to bring it it on him /if the
25 sun shines /it's not too bad

These stories indicated that the patients and family caregivers were often unable to predict those events that would cause an acute exacerbation event. As the following excerpts demonstrate, for example, patients and family caregivers alike did not know or were sometimes surprised when the patient became acutely ill:

CG7.1:

109 CG7.1: [coughs] She didn't get no cold this time /Once before
110 she get cold /Ah that was /bad too /But this time /she is only in the
111 house

P10:

70 P10: Now where the infections come from /I [h] can't tell ya
71 /I don't know /It's not there today [h] /Bang it's there tomorrow /Just
72 like that [coughs]

P12:

43 P12: [h] [-h] I don't] know what start it off ah /[h] Because um ah
44 /the first thing I did /I quit smokin' /That's two 'n a half years ago
45 /[h] and ah /seems to me it didn't help /[h] like you know ah

In addition, the evaluation phrases usually reinforced the participants' implied meaning already identified in the narrative and orientation phrases of these stories: i.e., that these signs (usual behaviours or circumstances) were used by these patients and family caregivers to define the beginning stages of an acute dyspneic episode. As the following evaluation phrases suggest, these participants used such indicators, in part, to determine when to initiate help-seeking behaviour. The participants' frequent references to time indicated that there was an association between the behaviour or appearance of the patient and when it was necessary—"time"—to seek help:

P5:

298 P5: They [*my feet*] still stay swollen /**then it's time**
299 that something else is building up too

CG5.2:

77 CG5.2: But like you can kind of
78 judge by his feet /. You know the bigger they get /**the sooner** he'll be
79 goin' in sort of thing [chuckles] /you know [taps table] And ah /an
80 his colour is always bad

P10:

47 P10: Ahm....there was signs /but there was only a sign lets say
48 for a **day** /or **two days** in advance

Finally, it is important to note that patients and family caregivers, in their descriptions of the circumstances surrounding acute exacerbation events, also included evaluation phrases suggesting that they frequently delayed help-seeking behaviour. As the following excerpts illustrate, part of the point of presenting their stories describing the circumstances of acute exacerbation events was to communicate this hesitancy to come to the hospital—"he waits", "I wait", "she try to delay"—even though participants knew the patient was acutely ill. Although not stated by the participants, this pervasive tendency to delay seeking help appears to be related to the impreciseness of the signs or markers of impending acute distress:

CG5.2:

56 CG5.2 /He he often he **waits** until
57 he's ah /..ah he gets panicky /An I'm sure that doesn't help with the
58 breathing process /He can't relax enough to /to get anything in/An
59 he starts getting panicky /An he realizes /"OK I've gotta go in the
60 hospital" /He ah [taps table] he **waits** [taps table] an he **waits** [taps
61 table] an he **waits** [taps table] /Um I think this time wasn't too bad
62 ./He didn't **wait** as long as he has **waited** in the past

P6:

255 P6: You know some people might come earlier /When they feel that
256 they need it /Right off the bat /I was told I **wait too long** /[hhh] An
257 I'm foolish too /I could get in really bad trouble that way

CG7.1:

60 CG7.1: But she try
61 to **delay** /To not go in hospital /she no like go in hospital /To stay
62 home

P10:

10 P10: Well yesterday was pretty bad /when I decided to come /When
11 I co' decide to come to the hospital /i'ts bad /'Cause I always **wait**
12 too long /I should come the day before /but I never do [taps table]
13 /It's always /keep **puttin' it off** /an **puttin' it off** /Some of these days
14 I'm gonna be too late

In summary, the stories about the circumstances and signs of acute illness illustrate the participants' knowledge of factors that actually precipitate an acute exacerbation event. What information patients have is related to their experience with these acute exacerbation events. They indicate that, although they cannot usually predict when the patient will become acutely ill, they nevertheless know when the patient is ill, but delay coming to the hospital until they are sure that they can no longer manage the breathlessness. The circumstances and signs that are used by these participants to indicate impending acute distress are patient-specific and understood within the context of the patients' own experience. What is striking in all these circumstances is the impreciseness of the circumstances and signs that are used by these participants when they talk of knowing when an acute event is happening. This sense of imprecision presents the perception of the need for vigilance or monitoring of behaviour to determine when to seek help.

Longer segments of narrative texts will now be presented as examples of causes of illness stories. Similar to other participants in the study, each included explanations of both the causes of chronic lung disease and the circumstances and signs of acute exacerbation events. Their stories are presented to illustrate the function of causes of illness stories in the development of an understanding by these participants of the patients as victims of circumstances beyond their control. In addition, these stories will illustrate that although patients and family caregivers use signs and patient-specific information to determine the occurrence of an acute exacerbation event, they also live with a sense of ambiguity and uncertainty in relation to their experience of acute exacerbations of the patient's illness.

P5, a retired miner, told stories that described the relative contribution of his smoking behaviour, work as a miner, and exposure to environmental pollutants to the development of his chronic lung disease. CG5.2, one of P5's family caregivers, talked of her understanding of the circumstances and signs associated with acute exacerbation events of her father's illness and her understanding of the causes of her father's chronic lung disease. In addition, these extended narrative segments present examples of the structure, content, and meaning in causes of illness stories throughout the interviews.

Case Example #5

P5, a 72 year old widower, had suffered with COPD for several years. He had lived alone in his own home since his wife's death from respiratory disease thirteen years before. His three daughters (CG5.1, CG5.2, CG5.3) resided in the community and over the last several years these women had shared the caregiving responsibilities related to their father's chronic illness—driving their father to doctor appointments and managing acute exacerbation events. Another woman also went into P5's home once a week to do his shopping and cleaning. Fifteen years ago, according to his daughters, because of his rapidly decreasing lung capacity, P5 was told by his doctor to quit smoking. He had, however, continued to smoke. All three of P5's daughters were also smokers although CG5.3 quit following her mother's death 13 years ago.

Over time P5's progressive chronic lung disease had become severely incapacitating necessitating numerous emergency hospital admissions because of acute dyspnea. For the last three years he had required continuous low flow oxygen therapy and except for visits to the doctor's office or hospital, had been housebound. P5 and his family had developed a strategy to manage his acute exacerbation events. The daughters had programmed a portable telephone with each of their phone numbers. Although his house was small, P5 never moved about his home without having the phone in hand. When he sensed acute distress he immediately contacted one of his daughters. Whoever was available came to P5's home without delay, called the ambulance, and accompanied him to the hospital. P5 was hospitalised on this occasion because of another acute episode of his chronic lung disease.

When I met him he was lying in his hospital bed with the head of the bed elevated about 30 degrees. He was receiving oxygen by nasal prongs and

had an intravenous infusion in situ for both antibiotic and steroid therapy. He was unable to say more than a few words without a breath and used pursed-lip breathing and accessory muscles in order to breathe. The interview was therefore conducted at the patient's bedside.

The following is the full text of two stories from P5's interview. Each story is again presented using Labov's method of transcription and structural categories. The analysis will demonstrate the importance of both the context of the story's telling and structure for understanding P5's explanations for the causes of his chronic lung disease. In the first story P5 talks about the relative contribution of his smoking behaviour and work as a miner in his development of chronic lung disease:

P5: Causes of Chronic Lung Disease Story #1

Sure I've smoked all my life /but I also put in 37 years at the mine

Story Stimulus:

528 PAT: /What do you think has led you to have this lung
529 disease?

Abstract/Evaluation:

530 P5: Well...that /The doc-you ask every doctor /he'll say smoking
531 /Sure I've smoked all my life /but I also put in 37 years at the MINE
532 PAT: Yeah

Orientation/Evaluation:

533 P5: And ah /...all of those years /I was exposed to SO₂ /NH₃ /NH₄
534 /NH₄S₂ /an I could go on with the chemicals

Complicating Action:

534 /and ah..the SO₂ that
535 we were in /...in order to be able to go from place to the other
536 sometimes /all you could do was crack an eye lid /'cause you
537 couldn't keep your eyes open

Evaluation/Generic Story:

537 /it was that strong /now when this SO₂
538 hits water /it forms sulphuric acid /...my theory is [chuckle] if you're
539 sucking it in your lungs /your lungs are wet /so there's bound to
540 be minute
541 PAT: Yeah
542 P5: portions of sulphuric acid

Resolution/Evaluation:

542 /and what does it do /it burns your
543 lungs /an it ah anything that an acid burns turns to carbon

Evaluation/Coda:

543 /....now ah
544 the smoking didn't help /in fact I still have two or three cigarettes a
545 day
546 PAT: Yeah

547 P5: When I start shaking too much /say "T'hell with it' /an it pacifies
548 me /ah...[swallows] to a degree anyway

P5 told this first story, a complex generic story, to outline an alternative causal explanation for what he thinks led to his development of chronic lung disease. The opening statements act as an abstract for the story. In part, they also perform an evaluative function identifying the purpose of the account. P5 begins his story, not answering my question, but by saying what doctors (in general) think cause COPD. He then talks of his own smoking behaviour in relation to his work as a miner, immediately implying that there is an alternative explanation for the development of his lung disease:

530 P5: Well...that /The doc-you ask every doctor /he'll say smoking
531 /Sure I've smoked all my life /but I also put in 37 years at the mine

P5's statement suggests that there are at least two ways that the topic of cause can be addressed when talking about the development of chronic lung disease. These beginning phrases make it clear that in this story P5 intends to explain how his work as a miner contributed to his chronic lung disease. The story is grounded in P5's experience of the health care system as a chronically ill COPD patient and his technical knowledge as a career miner. P5 dramatises what he believes is a general medical opinion regarding the cause of lung disease: i.e., that "every doctor", independent of individual circumstances would recognise smoking as the major cause of COPD. Conversely, P5's statement implies that miners in general would likewise recognise the relationship between industrial pollution and the development of chronic lung disease.

Further, both perspectives include P5's recognition of the importance of time in a causal explanation of a chronic disease like COPD where the symptoms usually only

present later in life. P5 has "smoked all his life" and counters this claim with the fact that he has also spent what could be reasonably understood as a comparable amount of time—a working lifetime—employed by a mining company. Thus placed in opposition to one another, these statements effectively establish the premise from which the story is to be told. In the story that follows, P5 outlines an alternative causal explanation.

His presentation of industrial pollution as a credible alternative to the accepted medical perspective as a cause for chronic lung disease is strengthened by the way in which P5 tells the story. For example, the orientation segment which follows the abstract includes a list of chemicals that formed a salient part of P5's work environment. The identification of these chemicals, for someone who has never experienced this kind of work situation, conveys in a concrete way, P5's perception of the magnitude of the air contamination in which he worked:

533 P5: And ah /...all of those years /I was exposed to SO₂ /NH₃ /NH₄
534 /NH₄S₂ /an I could go on with the chemicals

The use of specific names of the chemical compounds further enhances the rhetorical effect, in this case evidential, of P5's story and reinforces the development of a believable alternative causal account. The narrative phrases which follow this orientation segment also contain specific orientation information, again strengthening P5's alternative explanation. These phrases vividly place P5 in the midst of this contaminated environment:

534 /and ah..the SO₂ that
535 we were in /...in order to be able to go from place to the other
536 sometimes /all you could do was crack an eye lid /'cause you
537 couldn't keep your eyes open

The development of this alternative explanation is further advanced by the patient's inclusion of an evaluation segment in the form of a generic story. This second story

543 /....now ah
 544 the smoking didn't help /in fact I still have two or three cigarettes a
 545 day
 546 PAT: Yeah
 547 P5: When I start shaking too much /say "T'hell with it' /an it pacifies
 548 me /ah...[swallows] to a degree anyway

This first story is an example of a well constructed and complex explanatory story.

The story demonstrates the effective use of a layered and open-ended structure in the development of a reasoned explanation. It also illustrates that P5 developed his theory of what might have caused his lung disease from within the context of his own experience as a career miner and a patient with end-stage chronic lung disease.

The second story is again told in an attempt to answer the question of what causes lung disease. The causal factor talked about is presented as an alternative that, in part, incorporates an explanation for both his underlying chronic disease process and his experience of recurrent acute exacerbation events:

P5: Causes of Chronic Lung Disease Story #2

An I'm wondering /if I could 've caught a hi'-a bug of some kind

Story Stimulus:

686 PAT: So you think you'll be here about a week? /Your daughter said
 687 P5: Oh the last time I was here ten days
 688 PAT: Yeah
 689 P5: I come in on Friday the 13th /an I come out on the 24th
 690 PAT: Yeah

Evaluation/Abstract:

691 P5: [swallow] [hhh] /But I wish they had some way of knowing /....I
 692 picked up

Abstract:

692 /...I don't know if you got the time /but I got another
 693 theory here
 694 PAT: OK /I got the time

Orientation:

695 P5: I used to go to Las Vegas lots
 696 PAT: Yeah
 697 P5: After I retired /an I stayed a Four Queens Hotel /An it's an older
 698 hotel

Evaluation/Complicating Action:

698 /...An I started to notice /This is when I noticed that-it's somthin'
 699 was goin' screwy /Every time I'd come back from Las Vegas /I'd end
 700 up in the hospital
 701 PAT: Umhum

Complicating Action:

702 P5: And one time I went there

ask every doctor", to this point there is no clear explanation for his chronic illness:

691 P5: [swallow] [hhh] /but I wish they had some way of knowing /...I
692 picked up /...I don't know if you got the time /but I got another
693 theory here

The context of the story, an essential component if the remainder of the story is to be understood, is initially introduced by the following orientation segment. With these phrases P5 establishes that the setting for the development of illness was a routine vacation following his retirement. He includes specific details regarding the frequency of his holiday trips—"lots"—and identifies that he always stayed in the same accommodation—a certain "older" hotel:

695 P5: I used to go to Las Vegas lots
696 PAT: Yeah
697 P5: After I retired /an I stayed a Four Queens Hotel /an it's an older
698 hotel

The point of the story is more specifically and clearly outlined in a second evaluation section that momentarily interrupts the flow of the story. It is apparent that P5's intends, through this story, to explain why he believes his experiences of acute exacerbation events necessitating hospitalisation followed each holiday experience. P5 emphasises the evidential value of his explanation by both emphasising that this holiday was not a unique event and dramatising the conclusion of each holiday experience:

698 /...an I started to notice /This is when I noticed that 'it's somthin'
699 was goin' screwy /Every time I'd come back from Las Vegas /I'd end
700 up in the hospital

Rather than acknowledging either his experience as a COPD patient or a miner as possible factors responsible for his illness, P5 presents a second theory. "Somethin' goin' screwy" begs an explanation and P5 appeals to the idea of "Legionnaire's disease" as perhaps the mysterious cause that has precipitated his acute exacerbation events necessitating hospitalisation:

aetiology theory with another story. This next story is contained within the bounds of the original story and in many respects is merely a retelling of the second story. The preliminary orientation phrases again describe a "Vegas" holiday. One can assume that P5 made the same accommodation arrangements. The outcome of this repeat holiday story mirrors the resolution of the first telling—"it's the same bloody thing". Given this similarity, the supplementary story performs an evidential function and is therefore worth telling. By providing additional information it adds credibility to P5's second aetiology theory.

In summary, it is important to note that P5 presented two very different stories explaining possible reasons for the development of his chronic lung disease. His second story attempted to explain not only the reason for his underlying chronic illness, but also his experience of recurrent acute exacerbation events. Both stories illustrate the importance of the contribution of context and experience in P5's explanation of his chronic illness as well as the uncertainty/ambivalence experienced by this patient in his understanding of the cause of his chronic disease.

Case Example #6

CG5.2 was the youngest of P5's three daughters. She was a working mother, who, with her husband, was raising two young children. She lived only a few minutes from her father's home and over the last several years had regularly taken a turn caring for her chronically ill father. On this occasion P5 called this daughter when he developed breathing difficulty. CG5.2 arranged for a babysitter for her children and immediately went over to her father's home. From there she called an ambulance and accompanied her father to the hospital, remaining at the hospital to support him through the admission process.

The following is the full text of two stories from CG5.2's interview. In my analysis and presentation of these stories I am particularly interested in identifying and displaying some perception of this family caregiver's understanding of the circumstances and signs associated with acute exacerbation events of her father's illness and her understanding of the causes of her father's chronic lung disease. The first extended story excerpt was told in response to a question about her involvement in her father's current acute exacerbation event:

CG5.2: Signs of Acute Exacerbation Event Story

His colour is always bad

Story Stimulus:

54 PAT: OK /so what happened this time? /Your dad called you

Complicating Action:

55 CG5.2: Oh OK /aah /yeah he called me /and he said um /"I've gotta
56 go in /'cause it's ti'-I've gotta 'n" /you know

Evaluation/Generic Story:

56 /He he often he waits until
57 he's ah /..Ah he gets panicky /an I'm sure that doesn't help with the
58 breathing process /He can't relax enough to /to get anything in/an
59 he starts getting panicky /An he realizes /"OK I've gotta go in the
60 hospital" /He ah [taps table] he waits [taps table] an he waits [taps
61 table] an he waits [taps table] /Um I think this time wasn't too bad
62 .He didn't wait as long as he has waited in the past

Complicating Action:

62 /...Um..he called

63 me /He said he was gonna go in

Resolution:

63 /I called to make arrangements for

64 the kids /so I could go in with him

Evaluation:

64 /He waits 'til one of us gets there

65 before he calls the ambulance /he can't make it in a car

66 PAT: Yeah

Evaluation/Generic Story:

67 CG5.2: We tried to ah /well we we tried it in the past /An he's just

68 he's too um /The position that you're in /sitting in a car is too

69 /constrictive I guess? /I don't know /can't make it in a car /so he

70 calls the ambulance

Evaluation:

70 Usually within an hour or so of

71 getting in there /he's well not fine but like his colour's back /...He

72 could always tell like he /he's getting progressively worse

Evaluation/Generic Story:

72 But ah

73 his colour is very bad /He's always a like ah pasty grey colour /you

74 know /Kind of a very sickly colour /An he get's ah /..h'they well we

75 call 'em Fred Flintstone feet /He get's big /fat /almost like big club

76 feet /Just I don't know if it's from not /eh retaining water /or lack of

77 movement /I don't know what it's from /but like you can kind of

78 judge by his feet /. You know the bigger they get /the sooner he'll be

79 goin' in sort of thing [chuckles] /you know [taps table] and ah /an

80 /.../um

In this first story from CG5.2's interview the actual narrative event (a description of P5's call to his daughter regarding his transfer to the hospital) merely formed the framework for the evaluation segments of this account: i.e., a description of this family caregiver's understanding of some of the important circumstances and signs that normally occur during these acute exacerbation events (Labov, 1972). Narrative phrases, in response to my direct question, introduce the story:

54 PAT: OK /so what happened this time? /Your dad called you

55 CG5.2: Oh OK /aah /yeah he called me /and he said um /"I've gotta

56 go in /'cause it's ti'-I've gotta 'n" /you know

The narrative action is then interrupted by the first of three evaluation segments which take the form of generic stories. During the course of the account CG5.2 introduces four different signs or behaviours that, within the context of the story, appear to be synonymous with the occurrence of an acute exacerbation of her father's

that CG5.2 also associates these signs with her father's subjective claim of acute distress:

71 /...he
72 could always tell like he /he's getting progressively worse

That is, when her father states he is acutely ill there are visible physical clues that she has come to associate with his subjective claim of increased distress. Her statements suggest, for example, that she is now able to differentiate between subtle changes in appearance that differentiate acute distress from the changes in his appearance that have happened over time because of his chronic illness. For example, CG5.2 suggests that her father's now normal skin colour of "pasty grey" further deteriorates during periods of increasing acute respiratory distress requiring hospitalisation. Although her description as presented appears somewhat vague her use of the intensifiers "very" and "sickly" emphasise that the change, although subtle, is something she can, nevertheless, recognise:

72 /But ah
73 his colour is very bad /He's always a like ah pasty grey colour /you
74 know /Kind of a very sickly colour

A change in her father's colour is also the sign for this family caregiver that the care received in the hospital is effective. In the following statement from this evaluation section, CG5.2 implies that seeking help is appropriate behaviour as P5's colour improves shortly after he receives care:

70 /Usually within an hour or so of
71 getting in there /he's well not fine but like his colour's back

In addition, CG5.2 associates the description of her father's skin colour with statements about P5 oedematous feet in describing episodes of acute distress. She uses the image of a cartoon figure to create an immediately identifiable picture of her father's feet when they become so swollen that they lose their shape. It is clear from

CG5.2: The Causes of Chronic Lung Disease Story

But it's I mean it's s'you know sixty years of smoking

Evaluation/Generic Story:

159 CG5.2: He [P5] um he always attributes it to um /"Oh I must have a little
160 infection /I must have a little affection" /that's why he's feeling
161 worse /But it's I mean it's s'you know sixty years of smoking /an
162 smoking VERY HEAVILY for fifty of 'em anyway

163 PAT: Um

164 CG5.2: An I guess I sure the mine didn't help /You know /working in
165 the mine /He was never underground /But I mean they were working
166 in all kinds of gases /An you know noxious noxious fumes an what
167 not so /I'm sure that didn't help /But I'm pretty sure it's the smoking
168 that /you know

169 PAT: Sets him off

Complicating Action/Generic Story:

170 CG5.2: Yeah /He get's out of the hospital /He doesn't smoke the
171 whole times he's in the hospital /He he goes in for months an he
172 doesn't smoke /But he gets out an he starts smokin '

Evaluation:

172 /an I'm sure it's

173 just a lot of it's just habit

Complicating Action/Generic Story:

173 /Sitting at his kitchen [taps table] table /an
174 that's what he does [taps table] /He smokes /He does his crosswords
175 /or he sits at the computer /An smoke an do his crossw'

Coda/Evaluation:

175 /Er I

176 shouldn't say anything /I smoke myself /So does CG5.1 [taps table]
177 /Ah like CG5.3 quit CG5.3 quit a few quite a few years ago /...But
178 ah CG5.1 and I are still smokin' /An every time I see him layin' there
179 /..I vow you know /I see him layin' there gasping for air /You know
180 /it's like like a fish out of water

No conspicuous clues were given in the preceding turn to identify CG5.2's reason for telling the above story. CG5.2 simply began by introducing three factors which she associated with her father's lung disease. As presented, it appears that CG5.2 was both talking about the causes of her father's acute exacerbation events, and describing the underlying reasons for his chronic lung disease. The initial evaluation phrases suggest that she and her father disagreed about the primary reason for developing his chronic illness:

159 CG5.2: He [P5] um he always attributes it to um /"Oh I must have a little
160 infection /I must have a little affection" /that's why he's feeling
161 worse /but it's I mean it's s'you know sixty years of smoking

In these opening evaluation phrases CG5.2 also minimises P5's talk of infection

Summary

The preceding patient and family caregiver stories are examples of the the participants' understanding regarding the possible causes of a patient's underlying chronic lung disease and the circumstances and signs of acute exacerbation events. Their accounts demonstrate that the function of their causes of illness stories reflected those identified in other patient and family caregiver interviews. Their stories illustrated the importance of the context of the participant's experience both in the development and presentation of an explanation of causal factors and in the analysis and interpretation of that understanding (Blaxter, 1983). Embedded in the patients' and family caregivers' experiences of environmentally risky situations was a sense of patient blaming.

Analysis of the stories related to the circumstances surrounding acute exacerbation events and the factors associated with these events functioned to demonstrate that these patients and their family caregivers lived with considerable ambiguity. Their stories showed that they were either not always sure of the factors which precipitated acute events and used a number of signs as indicators that an acute episode was imminent. The number of precipitating factors identified by these participants was limited. They described vague patient-specific markers of acute distress: signs that were often not obviously related to acute respiratory distress. In addition, the stories as told by these participants demonstrated that in the midst of the ambiguity, they knew when the patient was acutely ill. Their understanding of the signs of impending acute dyspnea influenced their help-seeking behaviour.

CHAPTER 9

NURSE TEMPLATE STORIES

"COPD's are your most anxious people"

The ten nurses who participated in this study told a number of stories describing their care of patients hospitalised with an acute exacerbation of COPD. As previously indicated, each nurse who took part was caring for a patient who was also a study participant. It is important to note that it was not the intention of this work to assess either the appropriateness or the adequacy of the nurses' accounts of their care. Rather, as previously outlined, the purpose of this component of the research was to identify the meaning of an acute exacerbation of COPD for nurse caregivers by examining stories identified in the interviews with them.

As previously indicated these participants worked on in-patient units. Study patients cared for by the nurses had been admitted to hospital in acute distress but were transferred to the in-patient units and cared for by the nurse participants only after their condition had been stabilised in the hospitals' emergency departments. When asked about the patient's admission seven of the nurses told patient-specific admission stories. However, their accounts were brief and did not generally characterise the patient's admission as a crisis event. Rather, as one might expect, the nurses focused many of their stories on their work of caring for patients on the in-patient unit.

In their interviews, the nurses normally told more generic and kernel stories than first-person event-specific accounts (see Table 4, Appendix A). In these generic and kernel caregiving stories the participants talked of the physical and emotional

characteristics and behaviours of hospitalised COPD patients in general and the usual care that these patients received. These nurses commonly described the COPD sufferers' anxious behaviours, suggesting that COPD patients were "anxious" individuals and that anxiety played a central role in the patient's experience of dyspnea. They also told stories about the usual nursing management of patients who were breathless: i.e., the administration of oxygen therapy and routine medications, and the inevitable need to address the patient's anxious behaviour. Throughout the participant interviews a common pattern of patient attributes, behaviours and expectations, and nursing actions was identified—a pattern of common patient and nurse behaviours that I have labelled a COPD illness template.

The identification of an illness template or common pattern of patient behaviours and nursing actions illustrate that the nurses who participated in the study, regardless of the length or type of nursing experience, shared a more or less analogous understanding of this experience. For example, their stories demonstrated that as nurses they had a common understanding of the attributes and behaviours of acutely ill COPD patients and a routine way of approaching breathless episodes that occurred on the in-patient unit. Further, it was clear that the patient behaviour most frequently confronted by these nurses was anxiety. Their stories suggested that these participants usually characterised the patient's anxious behaviour as a personal attribute and important cause of acute breathlessness rather than a marker of the patient's increasing respiratory distress.

In this chapter I will examine the nurses' stories as accounts of their work with patients admitted with an acute exacerbation of COPD. The initial purpose of the discussion is to demonstrate that the groups of stories told by the nurses incorporated

elements of the nurses' COPD illness template. The discussion will focus on the nurses' usual care of patients hospitalised with an acute exacerbation of their chronic disease. I will particularly address the nurses' presentation of patients' anxious behaviours throughout the various stages of an episode of acute breathlessness. Further, I will discuss the function of these stories in the development of my understanding of acute episodes of breathlessness from the perspective of nurses.

As indicated above, these participants most frequently told generic and kernel stories. Within this story structure the evaluation phrases were often interwoven into the narrative segments of the nurse stories. Therefore, in order to illustrate the function of these stories, in contrast to previous chapters, the structure, content, and evaluation components of the included examples will be addressed together. Three extended narrative segments are included at the conclusion of the chapter. These segments include examples of stories that contain some aspects of the shared illness template of usual patient behaviours and common nursing care strategies found throughout the nurse interviews. The presentation of a detailed analysis of these individual stories is intended to explicate the analysis process and interpretation of these nurse stories.

Nurse Stories: Structure, Content, and Meaning

As already indicated, a pattern of particular patient and nursing care behaviours, identified in the nurse stories, constituted what I have designated a COPD illness template. Before examining these stories in detail, it is necessary to define the notion of template as used in the context of these accounts. In the following analysis, the concept of a template will refer to the application of a particular configuration of

behaviours and attributes to define and understand a specific group within society (i.e., COPD patients during an acute exacerbation of their chronic illness) (Harré, 1993). Implicit in the use of this concept is the understanding that the structure or group of elements that constitute a specific template predates its application to a particular individual or situation. In addition, the utilisation of what Harré, a social psychologist calls the "template principle", denotes a sense of permanence in the constituting elements of a particular template. Further, the template, when applied to a specific individual controls the interpretation of the behaviours or attributes observed. That is, according to Harré, such a process provides structure and predictability in the interpretation of the behaviour of individuals believed to be members of any particular group.

In the following discussion, the analysis of the stories told by the nurses will demonstrate that certain elements (behaviours and attributes) constituted the illness stories (template) used by these caregivers in the accounts of their care of hospitalised patients. The groups of stories describing physical attributes and behaviour, emotional behaviour, usual nursing care, causes of acute exacerbation events, and admission circumstances will be addressed in turn.

Physical Attributes and Behaviour Stories

Nurses told stories about the usual physical attributes and behaviours of COPD patients when they were hospitalised during an acute exacerbation event. The content of these stories implied that these nurses had, as part of their COPD caregiving template, certain expectations about the usual physical appearance and behaviour of individuals hospitalised with acute chronic pulmonary disease and, in part, represented

the appearance and behaviour of the patient they were presently caring for. The highlighted segments of the following three examples illustrate some of the physical attributes—"barrel chest", "pursed-lip breathing", "pale"—that comprised part of what appeared to be a readily available and common illness template routinely used by these nurses:

N6

27 PAT: Is she typical for you of patients who /you see on this floor
28 with COPD?
29 N6: No /she' eh not /she doesn't /like she doesn't look the typical
30 /ahm COPD /she's ah she's onl 'she's /well she's 60 /ah she she looks
31 young /to me /for being sixty /she doesn't look ah /like she's had a
32 lot of problems with lung..ah I' lung disease .um /like a lot of them
33 develop the barrel chest /an and are constantly hunched over an
34 breathing /you know /the they their muscles 'n /she doesn't seem the
35 typical /typical problem with //her lung disease

N8

65 PAT: OK /now um is he sort of like COPD patient's /for you? /Is he
66 sort of like the normal COPD patient for you or?
67 N8: Actually he's um not as a' /I don't find him as acute /right now
68 /ah the COPD's that I have had /are ahm...more short of breath
69 /than what he's showing /me he's he's t' he's not in acute /we've had
70 a few /but they were more acute than he was
71 PAT: Like what do you mean?
72 N8: Ahm /...more short of breath /he doesn't have the /the red red
73 red face /very wheezy /very audible wheeze /and I didn't find he was
74 doing much purse lipped breathing /I didn't notice that
75 /ahm..but..the only time he was short of breath was when he got up
76 to the bathroom /an that was one time when I was in there /and at
77 which time he put on the oxygen /an ah he was a little pale when he
78 returned from the bathroom

N10

77 N10: You know /but he /actually he's not as bad as a lot I've seen
78 /a lot of them /you you have to do chest physio /you have to fit that
79 in /these people can't hardly breath /but he's /he only has a little
80 spurts of it every now and again

In their evaluation phrases of the above excerpts the nurses indicated that the purpose of these physical attribute stories was to demonstrate that the physical characteristics of the patients they were describing did not meet their preconceived expectations of an individual with an acute exacerbation of COPD—"she doesn't look the typical", "I don't find him as acute", "actually he's not as bad as a lot I've seen".

Their use of contrast structures, (i.e., the comparison of this patient's physical attributes and breathing behaviour to a COPD illness template), strengthened their comparison of these patients with what they talked of as classic physical attributes: i.e., the patient either "look[ed] too young" or needed to be "more short of breath".

In addition, the nurses' use of rhetorical devices such as word repetition—"the red red red face"—and word intensifiers—"very wheezy, very audible wheeze"—also emphasised the presentation that this patient was or was not "typical". The inclusion of phrases like "a lot of them" or "these people" implied that these nurses either had previous caregiving experience or were aware of an illness template that they subsequently referred to when caring for COPD patients. Although not explicitly stated, these nurses consistently appeared to appeal to this previous experience or template in their evaluation phrases when accounting for their present judgements regarding the characteristics and behaviours of the patients presently in their care.

Emotional Behaviour Stories

Although the emergency room documentation clearly indicated that the study patients cared for by these nurses were admitted to hospital with an acute exacerbation of their chronic pulmonary disease characterised by intractable dyspnea, breathlessness was not the behaviour most frequently referred to by these participants. Rather, the behaviour most frequently described by these nurses was the patients' emotional reaction to their illness. These emotional behaviours (rather than the emergency nature of the event of intractable breathlessness) formed a major part of the nurses' stories and were invariably linked to the patient's experience of dyspnea or chronic disease in general. These behaviours were most often talked of as an expression of anxiety

rather than breathlessness. As demonstrated in the highlighted segments below, these nurses vividly described COPD patients as being "very anxious", "demanding", "complaintive", or patients who "set the rules":

N4

192 N4: Uum /don't want to stereo type a COPD /but a' as a-there's
193 probably a higher percentage I see of my patient's with this
194 diagnosis /is **more anxious than the other groups** that could be put
195 into heart or into diabetes /or into stroke /or [h] into tuberculosis
196 /or whatever /**COPD' s are very [h] anxious** /because seems like
197 they're breathin' their last /or they're/you know /one step away from
198 dying /or so they think

N5

207 N5: Yeah yeah /...oh I think they they seem to very um /precise in
208 their demands /like it's not /I'm not saying **they're demanding** /what
209 I'm saying is /they they know what they want and when they want it
210 /an how they like it /like they have a very set regime /a'in in their
211 everyday life as well as hospital like an
212 PAT: Yeah
213 N5: I mean I certainly think they could become **demanding** [laugh]
214 /but you have to set limits with them /an you just have to make
215 sure that /that you um can understand why they're asking the things
216 they're asking an

N5

52 PAT: /is he like /is he what you
53 would call your typical COPD patient having an acute episode?
54 N5: Yes I think so /I've I've had several COPD patients before
55 PAT: Yeah
56 N5: And um..t'they really **set the rules /set their limits /they set your**
57 **limits** [laughs] /th'th'they do they /they're the ones with the ah the
58 rules /because they are the ones that are short of breath /so they
59 have the /ah...they let you know when they're having a problem
60 /rather than your asking all the time

N8

87 PAT: Well what do you mean?
88 N8: To say a surgical COPD patient /or to
89 PAT: Well somebody that you would say /"Ah now this person is
90 acutely ill /with COPD"
91 N8: He's not /I think it's based on personality too /**he's not a**
92 **complaintive person /he doesn't complain that he's short of breath**
93 /but you can tell that he's short of breath /you can hear that he's
94 short of breath /but he's..'h see' v'he doesn't /**I don't think he's a**
95 **complaintive person** //you know

N10

131 N10: /**she's very anxious /but they are like that /they**
132 **are anxi'**--well I can't blame them /they get a hard time breathing
133 /**an they get anxious** /but she had a better day so far today than
134 yesterday /she gets chest pain too /on top of her breathing problems
135 /an then she just really gets /loses it /you know like /it's REALLY
136 gets

- 137 PAT: Oh does she?
 138 N10: Yeah really /it's just dadada [laughs] you know like really
- N12
- 61 PAT: Um what are these patients usually like? /I he ah /you look at
 62 him you say /"Ah this is a"
 63 N12: I he's a very nice man /but very ahm typical /very he gets very
 64 short of breath on exertion /ahm **I find him ahm...m' more relaxed**
 65 **than most COPD's /'n usually they're a little bit anxious** /because
 66 they breath--can't breath /an 'course /an he seems a little bit /doesn't
 67 seem to upset him /as ah much as others **/I find him very relaxed for**
 68 **a COPD**

In the above examples, these participants again included statements such as "my patients with this diagnosis" or "I've I've had several COPD patients before", rhetorical devices that presented their descriptions as typical rather than unique, implying their knowledge of some form of previously existing illness template. Then, within the context of their story, the nurses implied their use of this template by either confirming that their patient "fit" the behavioral template for a usual COPD patient admitted because of an acute exacerbation event—"they are like that"—or intimated that their patient was an exception to the their expectations—"he's not a complaintive person".

The use of contrast structures in several of the stories further emphasised the existence of some pre-existing template regarding the emotional behaviour of COPD patients. For example, N4, in the above excerpt from a story that will be examined in detail later in the chapter, stated that, from her perspective, COPD patients were "more anxious" than "other groups" of chronically ill patients. She strengthens her claim by actually listing other recognisable groups of patients also living with a chronic illness. N12, in the above excerpt, also compared the patient she was caring for (P12) with some form of behavioral expectation. The use of a contrast structure in this story also suggests her knowledge of a pre-existing COPD illness template.

Another rhetorical device identified in two of the above stories excerpts was the nurses' inclusion of a disclaimer when they talked about what might be construed as a negative behaviour: i.e., statements such as "I don't want to stereotype a COPD" or "I'm not saying they're demanding". These disclaimers potentially functioned either to distance the nurse from what might be labelled as a potential inappropriate judgement or to indicate that the behaviour of the patient they were presently caring for was being compared to an existing and essentially objective template of emotional behaviours, hence not a judgement of the nurse.

In the above story excerpts, it appears that the nurses were describing the anxious behaviours of COPD patients as one of the inevitable outcomes of an increased sense of breathlessness. In the following section of stories describing the usual nursing care of these individuals, it is apparent that anxious behaviour was talked of as both a cause and a result of an acute dyspneic event.

Usual Nursing Care Stories

Stories told by nurses about their work with COPD patients further demonstrated that these participants shared a broad and fairly common general understanding of the usual physical and emotional care (COPD illness template) required by, and provided for, any individual who was admitted with an acute exacerbation of their chronic pulmonary disease. Although, as indicated above, the most frequently described presenting patient behaviour included in the nurses' stories was some form of patient anxiety, the initial aspect of care consistently described by all participants addressed the physical needs of these patients. A number of the most commonly reported interventions used by these nurses, highlighted in the following excerpts, included

decisions about oxygen therapy—"give them oxygen, assessment of oxygen saturation levels—"check their O₂ sats"²⁹, the administration of p.r.n.³⁰ bronchodilators—"get them the Ventolin order", the positioning of patients in the most advantageous posture for easy breathing—"keep the head of the bed up", and chest auscultation³¹—"listen to their lungs":

N6

62 PAT: So do you do anything in particular /if they say call you down
63 to the room /an they're acutely short of breath?
64 N6: Well we'll see /we'll **get them the Ventolin³² order** /usually is the
65 **first /first thought** /you know if they /well wh' we usually give them
66 **O2 /put them the V' Ventolin on** /you know /**keep the head of the bed**
67 **up** /you know /to to promote the breathing

N11

183 PAT: Yeah /OK /um if they get in trouble what do you do? /say if
184 they have have dyspnea
185 N11: That's well /**check they're prn's** [laughs] /for one 'n you know
186 /if they have **O2 on /check their O2 sats /um listen to their lungs**
187 /and ah /**check what they have been doing**

In the above examples it is apparent that nurses initially spoke of the physical care they usually provided for patients during periods of acute distress in a specific sequence. The following narrative segments demonstrate that emotional or psychological care was also provided in combination with a more or less standard group of routine physical care interventions. The different emotional care strategies described by these nurses are highlighted in the following examples. The sequencing

²⁹ O₂ sats is an everyday expression used by nurses when referring to a patient's oxygen saturation level. Oxygen saturation refers to the amount of oxygen bound to haemoglobin in the blood. This assessment can be made at the patient's bedside and is used as indicator of the patient's respiratory status. A value less than 90% indicates respiratory distress (O'Toole, 1997; Smeltzer & Bare, 1996).

³⁰ p.r.n is an acronym for the Latin phrase "pro re na' ta"--"according to circumstances" (O'Toole, 1997, p. 1312). It is used by nurses to indicate situations in which they are able to use their discretion in the administration of medications or treatments (McKenry & Salerno, 1998).

³¹ Auscultation refers to the nurse's use of a stethoscope listen to the patient's breath sounds (O'Toole, 1997; Smeltzer & Bare, 1996).

³² Ventolin is the trade name for the drug albuterol, a bronchodilator, usually administered by means of an nebulizer or aerosol (Delglin & Vallerand, 1995).

of the physical caregiving strategies is again apparent:

N5

142 PAT: Yeah /OK /um do you do anything in particular when they say
143 get short of breath on you during a shift? //what would be if this
144 gentleman
145 N5: Ah ah] /well ah /first of all I'd put them in semi-fowlers /put the
146 oxygen on at two litres by nasal prongs /**talk to them really quietly**

N7

57 PAT: What do you do when ah patients get into distress?
58 /breathing problems?
59 N7: If they have a Ventolin or Atroven³³ order /we give it /or get
60 one /listen to their lungs /do O2 sats /give oxygen /**calm them down**
61 /**sit with them /reassure them everything's alright**

N8

183 PAT: OK /if he was in a' acute distress /what would you do?
184 N8: If he was in acute distress? /um I would put him in the bed
185 /elevate the head of the bed up /um ensure that his oxygen /was on
186 /um ensure that it was about 3 /litres /I wouldn't go any higher than
187 three litres until I know what his sats were /an until I knew /how he
188 was doing next /take a set of vitals³⁴ /um **try to provide a calming**
189 **atmosphere** /I find that helps /**encourage him t' //relax**

N9

107 PAT: So if if they call you in in distress /'n they ring the bell /an
108 they're in /having difficulty breathing /what would you do? /what's
109 your strategy?
110 N9: ...Well we listen to their chest /make sure that they're not filling
111 up with fluid
112 PAT: OK
113 N9: We check what O2 they're getting /ahm make sure it's /that
114 they're not getting more than prescribed /ahm they really should be
115 on medical air³⁵ /not our oxy' oxygen oxygen /I'll have to check
116 that too /I didn't put her on any /ahm and **deal with the patient in in**
117 **a calm manner** /trying t' t' to ease her /and sometimes um/they need
118 their puffers /a little maybe a little bit sooner

The presentation order of the usual nursing care strategies described by these nurses in the above examples suggests that their physical care interventions may have been arranged in a shared hierarchial order of importance, and that any form of

³³ Atrovent is the trade name for the drug ipratropium a bronchodilator, administered by means of a nebulizer or aerosol (Delglin & Vallerand, 1995).

³⁴ Vitals is an everyday expression used by nurses to refer to the measurement of blood pressure, pulse rate and respiratory rate (vital signs) (Smeltzer & Bare, 1996).

³⁵ Medical air is sometimes used rather than oxygen in the delivery of nebulised medication to COPD patients. COPD patients are at risk for developing oxygen toxicity when receiving supplemental oxygen therapy (Smeltzer & Bare, 1996).

emotional care was talked of as a final caregiving strategy. Although not explicitly stated, it is possible to speculate, based on the consistent structure of these stories, that these nurses viewed emotional care as an adjunct to the use of more technical interventions such as oxygen therapy and medication administration. In addition, the nurses' inclusion of strategies to reduce the level of the patient's anxiety during acute dyspneic episodes—"talk to them really quietly", "calm them down", "encourage him t' relax"—implied their recognition of a relationship between the patients' anxious behaviour and sense of breathlessness—the anxiety-dyspnea-anxiety cycle (Carriere-Kohlman et al., 1993).

In the above story excerpts, however, it is unclear as to whether the nurses were talking of dyspnea as the cause of patient anxiety or the reason patients behaved in an anxious manner. The relationship between acute breathlessness and anxious behaviour was again presented by these nurses in their stories of the causes of acute exacerbation events. However, in these accounts the nurses talked of anxiety as being responsible, at least in part, for the patient's sense of increased breathlessness. Excerpts from these stories will now be examined in more detail.

Causes of Acute Exacerbation Event Stories

In response to questions about what caused these acute episodes necessitating the patient's admission to hospital, these nurses told stories describing a variety of potential causal factors. Overall, their accounts of possible causal factors were imprecise since no clear contributing factor was described in any story. In addition, the nurses, even when asked directly, did not always clearly distinguish between the causes for the occurrence of an acute exacerbation event/illness or the emergency

hospitalisation of these individuals. Consistent with the other stories identified in their interviews, these nurses again frequently talked of anxiety or stress as one of the factors that may have contributed to a COPD patient's increased complaints of breathlessness.

The following story excerpts from the evaluation or generic story sections of a number of the nurse accounts demonstrate that for these nurses, although anxiety or stress was associated with acute distress, there was still a certain amount of ambiguity as to why patients became acutely ill and required admission to hospital during an acute exacerbation event. In the following segments, I have highlighted the potential reasons given by these participants in their talk of these events:

N3

107 PAT: What caused him to come in? /like ah /what causes these
108 acute episodes for these people?
109 N3: Could be the **weather** /..aah not taking /not taking his
110 **medication** /not being on bs'specific medication for COPD patients
111 /not being ah followed up closely /or close enough /...by the doctor

N4

38 PAT: Ah what you do think usually precipitates the acute exacerbation
39 N4: Different things /lifestyle /**anxiety** /ah **stress** /aah **exertion** /aaah
40 something **viral** sometimes /they contact in their environment /viral
41 or **bacterial** /um can be a number of these /or a combination of all
42 **those** /that I //mentioned

N5

120 N5: Um..I think part of the t'-I think part of it is **environment**
121 PAT: Umhum
122 N5: I there there's some that are **smokers** /'n an some of them that
123 in areas where there are um /...**some kind of..air problems** /OK /that's
124 number one /I think number two is sometimes **they come very**
125 **anxious** /something might ah **tick them off** /or get them all going
126 about something /they get into a problem with **anxiety** /um an I
127 think that p' part of it /I mean I think /**could be other reasons** /like
128 **medical reasons**

N6

42 PAT: Do you have an image in your head of what
43 N6: Oh what would set it off' ah
44 PAT: What you think /you say "Oh acute exacerbation of COPD"
45 /you say?
46 N6: Oh yeah /...well if they're a **chronic smoker** /that's you know
47 /that would cause a lot of problems /ahm.....just th' ah the **weather**
48 /like any you know /the **cold weather** /it might affect it

N9

35 PAT: OK /what I'm really want you to tell me about /today /is ahm
36 /why this lady came in /do you know why this lady came in? /what
37 happened to her?
38 N9: Ah possibility /although her daughter does administer her
39 medications /so /but I think sometimes /with the puffers /they ah
40 /they can't breathe /an they get anxious /they might overload on their
41 puffers /um they get anxious 'n /ahm stress /they get ahm they go
42 into one of their sp' /they'll go into a spasm or

N11

94 PAT: Yeah OK /what do you think usually brings these people to
95 hospital /even if you don't know specifically what brought him /in
96 your mind what--when you think of why they come in /what?
97 N11: Ah [clears throat] ah /a lot of the times when I read back in
98 the charts /you know /it's a recent cold or some other type of viral
99 illness that's exacerbated it /an got 'em going /sometimes stress I
100 find /they'll ah /they'll seem to have more than just that going on

As the above examples demonstrate, the nurses' descriptions of possible precipitating causes of acute exacerbation events necessitating hospitalisation included a combination of such things as anxiety (stress, ineffective coping), weather changes, infections, problems with medications, and life style factors (smoking, increased activity levels). Although several factors such as poor air quality, anxiety, and infectious agents reoccurred in a number of the participant's stories, it is apparent that these nurses, nevertheless, shared a sense of ambiguity about the possible causal factors (COPD illness template). A closer examination of the above story clauses demonstrates that the nurses also used rhetorical devices that distanced them from a commitment to any specific causal factor. For example, factors such as stress and weather, in the nurses' words, "could", "might", "possibly" be related to an acute event.

Analytically, several elements of these stories appeared to underline the relative importance of this information in the nurses' understanding of an acute exacerbation event. As illustrated in the above examples, the limited and imprecise nature of the causal information in some measure implied that this information was not central to

the work of these nurses in their care of patients hospitalised for an acute exacerbation event on an in-patient unit. The nurses' stories about the admission events of these patients, to be addressed in the following section, further illustrate that these participants essentially talked of their work on the in-patient unit.

Admission Stories

Several nurse admission stories, usually located at the beginning of the interviews, were told in response to a direction question about the patient's current illness and why they had come to the hospital. Two factors, fundamental in my interpretation of this event from the perspective of these nurses, were identified in these admission stories. First of all, it was apparent that these nurses were either unaware of the patient's admission circumstances or told a limited number of minimal stories that talked of the patient's preadmission circumstances. For example, three of the participants stated that they did not know what had happened necessitating the patient's hospitalisation. They excused this lack of information by pointing out that they had not been the admitting nurse, had not spoken to the patients about their illness, or had not had a chance to read the admitting notes on the patient's chart. The remaining seven nurses either referred to the patient's chart for information regarding the patient's admission or told only short stories when describing what they knew of the patient's admission. Secondly, although the nurses did describe patient-specific preadmission details in the stories they told, they all spoke of a form of "shortness of breath" as the common reason why these patients had come to the hospital (part of the shared COPD illness template).

The following short excerpts from several nurse stories illustrate that these nurses,

regardless of their nursing experience, told only limited accounts of their patient's admission and appeared to share at least one common understanding of why these patients came to the hospital, namely that the patient was short of breath. As illustrated in the highlighted sections below, the essential point of telling each of these minimal stories, regardless of the patient's particular circumstances, was to communicate that the patient ultimately came to the hospital because of their dyspnea:

N3

34 PAT: /OK /so what I want you to
35 tell me though /is um....if you know how this patient got sick this
36 time?.../it doesn't matter if you don't but?
37 N3: I asked him] /and he said he's been coughin' for about two months
38 /and he wanted to go to the hospital /but I think his wife an family
39 said "No no no /we'll see the doctor instead" /an he said "No /I'm goin'
40 to the hospital now /'cause **I can't breathe anymore** /an I can't take
41 no-like much longer of this" an they brought him in /an he was
42 admitted
43 PAT: OK
44 N3: That' all I know

N4

5 PAT: Yeah /I want you to first /tell me what you know about ah
6 /how he got sick this time
7 N4:Aah ..basically he has um /Mr P4 has COPD /and when it
8 get's under control and whatever he goes home /this time it just
9 went out of control /an **he was with shortness of breath** /an an
10 expiratory wheeze

N6

13 PAT: Now /do you have any idea why /this lady /came to the
14 hospital at this time?
23 N6: /but just ah generally /like I think she was on antibiotics prior
24 to admission /and ah they were stopped a couple of days before
25 /and [turns chart pages] she went into the exacerbation /**she went**
26 **into shortness of breath** /respiratory distress /and ah..that's about it

N7

16 PAT: OK /so . do you know why she came to the hospital this time?
17 N7: **Shortness of breath** /uum her-she was having a cold for about a
18 week /**shortness of breath** /having trouble breathing /ahm bit of a
19 cough /heaviness /so she came in /to emerg

N8

16 PAT: Do you know what happened to him /why he came?
17 N8: Ahm **short of breath** /his puffers /he was taking his
18 puffers /be believed they /he was out /so he came in through the
19 emerg department /that's the extent I know

N10

13 PAT: OK /now /do you know why he came in? /what happened to
14 him?
15 N10: **He was having a very hard time breathing** at home /more so
16 than he usually did //and that's why he came in

N12

32 PAT: /ahm can you tell me what happened to him?
33 N12: He ahm /he has been in the hospital apparently for--ah this is
34 the third time in a month /and ah he just went home /I think he said
35 approximately two weeks ago /not even /and was readmitted with
36 ah **shortness of breath**

The preadmission events spoken of by these nurses in the above excerpts included a variety of patient-specific information. For example, some nurses talked of the patient's concerns regarding an ongoing infection or difficulties with a medication the patient was receiving. Others participants simply stated or implied that the patient was short of breath and therefore came to the hospital. The simple structure and content of these nurse admission stories, as illustrated in the above examples, however, contrasts sharply with the drama portrayed in the patient and family caregiver admission stories discussed earlier. The above story excerpts, for example, do not describe an emergency situation. There is limited description of intractable dyspnea, and except for the story presented by N3, a story which will be examined more completely later in the chapter, there is no account of help-seeking behaviour or family involvement in the stories of these patients' emergency admissions to hospital.

Based on the omission or brevity and simple nature of the nurse admission stories, it is possible to speculate that these participants used only a limited amount of preadmission patient information in the planning of care for these individuals during their hospital stay. As a group (part of their COPD illness template) they recognised that these patients, in conjunction with other specific circumstances (usually poor air quality, anxiety, an ongoing minor infection, or medication difficulties), ultimately

came to the hospital because they (as COPD patients) were "short of breath". Nevertheless, their stories suggest that the reasons for seeking help did not impact on the care that they provided.

Nurse Stories: Function

In summary, the nurses told a number of stories (predominantly generic and kernel) describing their experience of caring for patients with an acute exacerbation of their COPD. The central function of these stories was that they revealed that these nurses spoke of a more or less common COPD illness template comprised of elements of this experience. As already discussed, this template included elements related to the nurses' perceptions about the COPD patients' physical attributes and behaviours, their emotional behaviour during episodes of acute respiratory distress, the causes of acute exacerbation events, and the usual care provided by these nurses. In addition, their stories demonstrated that this pre-existing illness template functioned both as the structure used by these nurses in their interpretation of the behaviours presented by patients during an acute exacerbation event and as a guide in the planning of their nursing care actions during episodes of acute respiratory distress.

Interpretation Function

The identification of an illness template in these caregiver stories demonstrated that the interpretation of certain aspects of an acute exacerbation event such as the causes of acute episodes and the meaning of patient physical and emotional behaviours, were informed by the elements of this structure. For example, one could speculate that the brevity of admission stories and the ambiguity of causes of illness accounts implied

that these nurses used their usual understanding to inform the care that they provided for specific patients; that for these nurses, patient-specific information was not seen as being essential in their provision of care on the in-patient unit.

As already discussed, emotional distress was the most common behaviour described by the nurses in their care of hospitalised COPD patients. These participants consistently implied that anxiety was an important cause of breathlessness in these patients. Their stories functioned to illustrate that this perception (element of their COPD illness template) influenced their interpretation of the anxious behaviour of all hospitalised COPD patients. These nurses, when confronted with the anxious behaviour of a COPD patient in acute distress, consistently interpreted such behaviour as an essential cause of the patient's acute distress.

Care Planning Function

Further, as indicated, the nurses' illness template also included a description of the nurses' usual work with patients hospitalised because of an acute exacerbation event. These stories functioned to illustrate the nurses' use of the COPD illness template in their description of the usual care of acutely ill COPD patients. In their stories these participants suggested that the care of patients admitted because of an acute exacerbation of COPD, regardless of the cause, was essentially the same.

The following case examples include stories told by three nurses about their care of patients hospitalised with an acute exacerbation of COPD. The intention of including the detailed analysis of these extended narrative segments is to illustrate that, like the other nurses in the study, these participants told stories about their work within the context of a more or less consistent COPD caregiving template or group of

generic stories. The presentation of these particular stories also demonstrate the function of this template in explaining or accounting for the nurses' assessment and/or care of hospitalised COPD patients. Finally, these extended narratives highlight the prominence of the patients' anxious behaviour in the nurses' accounts of acute episodes of chronic pulmonary disease.

Case Example #7

N3 had practised as a registered nurse for four years. For the last three years she had been working on a medical unit responsible for a variety of acutely ill patients including acutely ill COPD patients. N3 was the admitting nurse when P3 arrived on the in-patient unit and cared for him for the first three days of his hospital stay. P3, a tall, heavy set, barrel chested 88 year old gentleman, had a long history of COPD. When I spoke with P3 and his wife (CG3.1) on the third day of his hospitalisation, he was obviously short of breath. During the interview he used neck and shoulder muscles to breathe and was unable to complete a sentence without taking a breath. He was on continuous oxygen by nasal prongs. Although N3 had met P3's wife, she had not spoken to her about her husband's illness or the management of his care at home.

Two linked stories are included from N3's interview. Elements of the previously outlined COPD illness template can be identified in N3's stories. In addition, the first story illustrates that this nurse did not see the patient's admission as a crisis event necessitating emergency hospitalisation. It is also apparent that the commonly held perception that COPD patients are anxious was used by this nurse to explain/account for a particular aspect of this patient's behaviour and justify some of her nursing care actions. The first-person event-specific story was told by N3 in response to a question about "how this patient got sick this time":

N3: Admission Story

That's all I know

Story Stimulus:

34 PAT: /OK /So what I want you to
35 tell me though /is um.....if you know how this patient got sick this
36 time...//It doesn't matter if you don't but

Orientation:

37 N3: I asked him]

Complicating Action:

37 /and he said he's been coughin' for about two months
38 /And he wanted to go to the hospital /But I think his wife an family
39 said "No no no /We'll see the doctor instead" /An he said "No /I'm goin
40 to the hospital now /'cause I can't breathe anymore /An I can't take
41 no-like much longer of this"

Resolution:

41 /An they brought him in /An he was

42 admitted

43 PAT: OK

Coda/Evaluation:

44 N3: That's all I know

The story as presented by N3 initially appears to be an uncomplicated account of the events preceding and precipitating his admission to hospital. An interpretation of these events by N3 in the form of separate evaluation clauses was not included in the storytelling. N3 simply states that P3, who had been sick for approximately "two months", decided that "he wanted to go to the hospital". According to the story, his request was rejected most probably by his wife and at least one other unnamed family member who also made an alternative suggestion of going to see the doctor. However, P3 was eventually brought to the hospital and subsequently admitted.

Although specific evaluation statements were not included in the story, the evaluation elements that serve to minimise the acute nature of P3's illness by N3 are embedded within the narrative clauses themselves. For example, through the narrative phrases as presented, N3 implies that this patient was admitted to hospital because he wanted to be admitted rather than an episode of acute distress; that his wife thought his condition could have been managed by a visit to the doctor rather than emergency hospitalisation; and that his hospitalisation was probably a result of his demanding behaviour rather than his acute distress. The use of the rhetorical device of dramatising the verbal exchange between family members and the repeating of their words and statements within the context of this interview, further served to minimise the

seriousness of P3's complaints and reinforce the perception that the significant factor precipitating P3's hospital admission was not breathlessness, a medical crisis, but rather his demanding behaviour:

The characterisation of P3 as a desperate or anxious man as opposed to being a COPD patient who was experiencing unusual dyspnea resulting in anxious behaviour is further developed in the following more complex story describing a series of events which occurred following P3's admission to the nursing unit. In this second story P3's anxious nature appears to have been interpreted by N3 as the factor that accounted for P3's "demanding" behaviour. Such behaviour then explains and justifies her nursing actions. It is important to note that there is no mention of breathlessness in this second story:

Story Stimulus:

Abstract/Evaluation:

Re-orientation/Story Stimulus:

Evaluation:

Complicating Action:

Evaluation:

Orientation/Evaluation:

143 /Because in emerg /he said like the nurse was right beside
144 him /An he got everything now

Complicating Action:

144 /An at that time I explained to him
145 that /You know /"We have eight other patients /There's 38 on the floor"

Orientation/Generic Story:

146 /He called /H'he keep calling t'the call bell until we do come /But
147 usually we don't make them wait that long /And if he waited..two three
148 minutes /It's about it

Complicating Action:

148 /Uum..but I didn't have a chance to look at the
149 chart /The night-an the next day /The night nurse said that she had to
150 ah call the doctor for Xanax³⁶ /'Cause he was on that at home /for
151 anxiety /And he settle for the night /with that

Resolution:

151 /An and that same day-
152 next day when I came on /I asked the doctor to get some ah Xanax
153 during the day /An he just put him on Librium /3 times a day //An
154 that was started
155 PAT: Oh]
156 N3: For his anxiety

Evaluation:

156 /So he was really anxious

Coda/Evaluation:

157 PAT: Ah is this something you have seen? In COPD //patients
158 N3: No] no not really /Just when they get those fits /You know they
159 want /When they're gasping for air and you can't /get it /They get
160 anxious at that time /But otherwise /I think it's-I don't think it's
161 common /I don't think so

This second story is a more complex event-specific story. The problem as identified by N3 is that she is caring for "an anxious man" whose behaviour must be understood within this context. This story performs two functions. Firstly N3 uses the story to explain P3's behaviour as an anxious COPD patient and to account for her nursing care. Secondly the story illustrates my contention that nurses refer to a typical caregiving template to help them both understand and explain their own work. The story structure and content facilitate the accomplishment of both of these functions as described below.

First of all, the story appears to fall into three segments which describe the

³⁶ Xanax is the trade name for the drug alprazolam, an anxiolytic or mild sedative (Delglin & Vallerand, 1995; O'Toole, 1997).

narrative events over a two day period. The first segment describes P3's transfer onto the medical unit where N3 works. Although the clauses describing this event are clearly narrative, they also provide essential orientation information: i.e., it is during the admission process that N3 first observes P3's anxious behaviour requiring medication ("mask" or inhalation therapy). An element of evaluation is embedded in these narrative clauses. For example, with the activity of the transfer, N3 states that P3 became "a little bit hyper" and describes his response to the bronchodilating medication ("mask") as "he settled". An alternate story might have stated that with the increased activity P3 became breathless and that the "mask" relieved his breathlessness. It appears that, on this occasion, although N3 gave medication for breathlessness, the presenting behaviour was that of anxiety, by implication inappropriate.

The second event segment of the story involves a confrontation between P3 and another nurse. Although the patient's behaviour is not explicitly described, N3 once more highlights the inappropriateness of P3's actions. As before, the events described concern the administration of inhalation therapy, however, the behaviour described is P3's expression of anxiety, this time in the form of "VERY demanding" behaviour, again not shortness of breath. This narrative segment is interrupted by an evaluation segment and orientation information. In both groups of clauses N3 suggests that P3's behaviour was unacceptable both because of the nature of the behaviour itself ("VERY demanding") and also because of his inappropriate comparison between the ward situation and emergency room environment:

141	/He was VERY demanding at that time /He didn't
142	understand how come he could'a /How he made-we made him wait
143	that long /Because in emerg /he said like the nurse was right beside
144	him /An he got everything now

N3 concludes the narrative segment of the story by talking of two alternative interventions to potentially deal with P3's anxiety ("VERY demanding") behaviour. The first was to imply that the caregiving responsibilities of nurses on this unit, in comparison to those assumed by the emergency room nurses, is much greater: i.e., eight patients at one time and perhaps as many as 38 when the nurses are busy or off the floor for their meals:

The second was to suggest that even given this workload, the nurses acted responsibly by "usually" limiting the time patients waited for medication administration. N3 states that P3's wait was only a few minutes. Her use of the contrast structure of P3's continued use of the "call bell" and the nurses' swift response to his request again further served to highlight the inappropriateness of this patient's "demanding" (anxious) behaviour.

151 /An and that same day-
152 next day when I came on /I asked the doctor to get some ah Xanax
153 during the day /An he just put him on Librium³⁷ /3 times a day //An
154 that was started

³⁷ Librium is the trade name for the drug chlordiazepoxide, a sedative/hypnotic (Delglin & Vallerand, 1995; O'Toole, 1997).

for N3 "demanding" behaviour and anxiety are part of a typical story of an acute exacerbation event. Anxiety is the behaviour that she must attend to when caring for patients admitted with shortness of breath:

158 N3: No] no not really /just when they get those fits /you know they
159 want /when they're gasping for air and you can't /get it /they get
160 anxious at that time

What remains unclear or ambiguous is the nature of the relationship between breathless and anxious behaviour. Throughout the story P3 is described as an anxious patient. The account as presented by N3 implies that he was also breathless, however, the story as told, implies that this patient was responsible, at least indirectly, for his breathlessness.

Case Example #8

N4, a medical nurse for 20 years, had worked on the same medical unit for most of her nursing career. Patients with acute exacerbations of COPD who came to the hospital for care were usually admitted to this unit. N4 was eager to assist in research aimed at enhancing nurses' understanding of acute exacerbations of COPD. She had been caring for P4, a 60 year old man with a long-standing history of COPD, since his admission two days before the interview occurred. She had also looked after this patient during another hospitalisation, approximately eight months earlier. On that occasion P4 had experienced a respiratory arrest during her shift and before the interview N4 told me that she had assisted in transferring this patient to the intensive care unit for intubation³⁸ and mechanical ventilation. She was aware that P4 was a widower, but had never met any members of his family and was unaware of his living arrangements.

Two stories are presented from N4's interview. In the first story N4 describes why P4 came to the hospital this time. In the second she describes the relationship between anxiety and breathlessness in individuals hospitalised because of an acute exacerbation of their chronic pulmonary disease. Analysis of the first story will suggest that this caregiver, although unaware of why P4 came to the hospital this time, did refer to a COPD illness template when talking of why COPD patients are usually hospitalised. In addition, the following analysis of both stories will highlight the function of anxiety, another element in a COPD illness template, in this nurse's explanation of the causes of acute episodes of dyspnea and in her account of the usual care of patients

³⁸ Intubation refers to the insertion of "...an endotracheal tube through the nose or mouth into the trachea. Intubation provides a patient airway when the patient is having respiratory distress that cannot be treated by simpler methods (Smeltzer & Bare, 1996).

admitted with acute exacerbations of their chronic pulmonary disease:

N4: Story of Causes of Acute Exacerbation Events

He can be an anxious fellow to begin off with

Story Stimulus:

38 PAT: Ah what do you think usually precipitates the acute exacerbation

Abstract:

39 N4: Different things /lifestyle /anxiety /ah stress /aah exertion /Aaah

40 something viral sometimes /They contact in their environment /Viral

41 or bacterial /Um can be a number of these /or a combination of all

42 those /that I //mentioned

Re-orientation/Story Stimulus:

43 PAT: OK .Yeah /Do you have any specific per'perception of what

44 triggers this guy's ah acute exacerbations?

Complicating Actions:

45 N4: Well ah [hh] /He's not on any antibiotics I don't believe [turns

46 pages in chart] /Uum... probably /Oh he is on Gentamycin here

47 /sorry

Evaluation:

47 /Yeah /Uum possibility it might have been a cold or something

48 /or some type of viral bug that he picked up /and..He can be an

49 anxious fellow to begin off with /An he picked up probably this bug

50 somewhere

Complicating Action:

50 /An he was coughing up greenish stuff

Evaluation:

50 /An h'might

51 develop pneumonia or /you know /the start of pneumonia or

Complicating Action:

51 /But

52 doctor scared that he was at risk for it an

Evaluation:

52 /with him breathing so

53 hard and him coughing this up /Although I don't think he was-had a

54 high temp when he first came in /Of course I didn't have 'im when he

55 first came in /But..this probably is what precipitated him coming into

56 emerg /An him being admitted

This first of N4's two stories was told to address the issue of what precipitates an acute exacerbation of COPD. The story can be divided into two sections: i.e., the abstract phrases at the beginning of the story in which N4 states her opinion as to the relative importance of various factors in the precipitation of an acute exacerbation of chronic pulmonary disease; and a second section, an event-specific account of what actually precipitated this acute episode of P4's chronic illness.

In the opening abstract clauses, N4 presents a list of the usual causes of acute exacerbation events. The list includes two categories of possible factors that potentially

explain the occurrence of acute exacerbation events: i.e., emotional factors such as "anxiety" and "stress"; and physical factors such as "viral or bacterial" infection, "exertion", and undefined "environmental" elements. The ordering of the list, as presented by N4, implies that there is a hierarchical relationship between the possible causes; that emotional factors—"anxiety", "stress"—play a more important role in the development of acute exacerbation events than factors such as "exertion" or infections.

This potentially contentious perspective is modified somewhat by N4's inclusion of qualifying statements at the beginning and end of the abstract section. The qualifying clauses ("different things", "a number of these", "a combination of all of those") suggest that, regardless of the relative importance of each named factor or her perception of the importance of emotional factors, no simple explanation for why patients experience acute episodes of their chronic pulmonary disease is available.

The story which follows presents N4's interpretation of the reasons for P4's present admission and stands as an example of the ambiguity implied in the abstract. In this section N4 revisits the two categories of factors (emotional and physical) that were previously described. She read the chart during the interview and indicated that she was unaware of the documented information of a possible infection. In the evaluation section which follows the narrative statements, it is apparent that, even given the documented evidence of some form of possible infection process ("oh he is on Gentamycin"), N4 presents P4's anxious behaviour ("he can be an anxious fellow") as a concomitant predisposing factor in his development of an acute episode of breathlessness:

47 /Yeah /Uum possibility it might have been a cold or something
48 /or some type of viral bug that he picked up /and..He can be an
49 anxious fellow to begin off with /An he picked up probably this bug
50 somewhere

In the concluding evaluation phrases N4, in the process of telling the story, visibly works through her understanding of what she now believes may have caused P4's present acute exacerbation event. In these clauses N4 juxtaposes difficult breathing and sputum production with the possibility of P4 developing pneumonia. She suggests, however, that pneumonia would be characterised by an elevated temperature—"high temp". What is unsaid but implied by N4's evaluation phrases is that P4 found himself in this position ("breathing so hard" and ill enough to be hospitalised), at least in part, because "he can be an anxious fellow". It is apparent that the anxiety component of N4's illness template or usual illness story, provides N4 with part of the explanation of P4's acute breathlessness.

A second story presented later on in the interview again illustrates N4's utilisation of a usual illness template to explain behaviour when caring for patients with acute exacerbations of COPD. Specifically, this story discusses the importance of anxiety as both an important causal factor for acute dyspneic episodes and the result of an increased sense of breathlessness. The following generic story was told in response to my statement suggesting that individuals experiencing an acute exacerbation event came to the hospital because they were afraid that they were dying.

In the ensuing story, N4 suggests an alternative and broader interpretation of the COPD patients' behaviour than the patients' and family caregivers' interpretations of acute exacerbation events as a medical crises. Her story highlights two interdependent explanations: i.e., that these individuals are anxious because of the frightening nature of breathlessness, and that patients precipitate acute breathlessness by their anxious behaviour. N4 includes three generic story segments to support her claim that COPD patients' anxiety contributes to their sense of breathlessness. She suggests that

sedatives are often prescribed to both prevent and treat acute exacerbation events, that individuals with COPD are different from other groups of chronically ill patients and that this group of patients would label themselves as anxious:

N4: Story of Causes of Acute Exacerbation Events

A lot-COPD's are your most anxious people

Story Stimulus:

173 PAT: OK /um so ...um maybe that' not a really good question but
174 /his his perception of it /an people I've talked to /is that they they
175 think they're going to die /That's that's when they come here /They
176 think they're going to die /That's when they come to the hospital /That's
177 the-they think it's-if they don't come here they will die //ah

Abstract

178 N4: A lot-COPD's are your most anxious people /They're highly
179 anxiety

Evaluation:

179 /But I mean if it feels like every breath is their last /Of course
180 they're probably gonna have this idea /Gonna be ah ah statistic /Like ah
181 fatality or whatever

Complicating Action/Generic Story:

181 /And ahyeah lot of times I can-I will hear
182 that /"I think I'm gonna die" /I before they're goin into respiratory
183 crisis /or "I can't catch my breath"

Evaluation:

183 /Um.....but a lot of COPD's
184 /especially if they get very very anxious /Can make the respirations
185 worse or whatever /So you have to depend if there's a crisis there
186 or not

Generic Story/Evaluation:

186 /Sometimes just havin' the doctor /say "All that patient really
187 needs is an Ativan³⁹" /The respirations will become much easier again
188 /...you know

Re-orientation:

189 PAT: So you think there is ah an anxiety component to this //for
190 N4: For] COPD's
191 PAT Yeah

Evaluation/Generic Story:

192 N4: Uum /don't want to stereotype a COPD /But a'as a-there's
193 probably a higher percentage I see of my patients with this
194 diagnosis /is more anxious than the other groups that could be put
195 into heart or into diabetes /or into stroke /or [h] into tuberculosis
196 /or whatever

Evaluation/Generic Story:

196 /COPD' s are very [h] anxious /because seems like
197 they're breathin' their last /Or they're /you know /one step away from
198 dying /Or so they think
199 PAT: Yeah
200 N4: And a LOT a LOT are on nerve pills

³⁹ Ativan is the trade name for the drug lorazepam, an anxiolytic or mild sedative (Delgin & Vallerand, 1995; O'Toole, 1997).

Generic Story:

200 /When they come in /the

201 doctors are givin' them sedatives

Evaluation:

201 /And I don't know if it's counter-

202 effecting that after a while but

Generic Story:

202 /a lot of them /COPD's are very

203 insistent that they get something /to relax their nerves

204 PAT: Yeah

Evaluation:

205 N4: And a lot of them realize that they are a nervous bunch of

206 people

N4 begins her story by addressing my statement that patients come to the hospital during an acute exacerbation event because "they think they're going to die". The abstract presented by N4 outlines the essential point of the story to follow: i.e., individuals with COPD are anxious people. Her statement implies that this characteristic influences the patients' experience of breathlessness:

178 N4: A lot-COPD's are you're most anxious people /They're highly
179 anxiety

In the story which follows, N4 presents this claim in three ways: i.e., first of all by describing the usual situations of respiratory distress which are managed, in part, by anti-anxiety agents; secondly by comparing COPD patients with other groups of chronic illness patients; and finally by using the patient's own words.

For example, N4 begins by suggesting that anxiety is the result of breathlessness ("respiratory distress"); anyone who experiences respiratory distress would reasonably be anxious:

181 /And ahyeah lot of times I can-I will hear
182 that /"I think I'm gonna die" /I before they're goin into respiratory
183 crisis /or "I can't catch my breath"

N4's use of the rhetorical device of direct quotations and reference throughout the story to a group of patients ("lots of times") reinforced the believability of her statements that breathlessness is a frightening experience. Further, her talk implies that

although these patients think they are "gonna die", this perception is related not to their breathlessness but rather to their experience of anxiety. When these patients (allow themselves to) become anxious during dyspneic episodes, they experience increased breathlessness:

These evaluation phrases reinforce N4's previously implied perspective: i.e., that sometimes a patient's anxious behaviour precipitates breathlessness that is not really a "crisis". When this happens N4 states that if the anxious behaviour is managed (treated with anti-anxiety medication, "Ativan"), the breathlessness will subside ("the respirations will become much easier again"):

As suggested, N4 also presents her claim that individuals with COPD are anxious people, a characteristic that influences their experience of breathlessness, by contrasting their behaviour with other patient groups. A four-part, open-ended list of well known illness groups is used to reinforce N4's claim that COPD patients are more anxious. Her statements imply that individuals suffering from these other conditions, also chronically ill and hospitalised because of an acute exacerbation of their illness, do not behave in the same anxious fashion as COPD patients. One is therefore to infer that it is the anxiety of COPD patients, associated with their intractable breathlessness, that causes them to believe that they are "one step away from dying":

196 /COPD' s are very [h] anxious /because seems like
197 they're breathin their last /Or they're /you know /one step away from
198 dying /Or so they think

Finally, N4 makes her claim that individuals with COPD are anxious people, a characteristic that implicitly influences their experience of breathlessness, by stating that COPD patients realise they are "a nervous bunch of people":

200 N4: And a LOT a LOT are on nerve pills /When they come in /the
201 doctors are givin them sedatives /And I don't know if it's counter
202 effecting that after a while but /a lot of them /COPD's are very
203 insistent that they get something /to relax their nerves
204 PAT: Yeah
205 N4: And a lot of them realize that they are a nervous bunch of
206 people

N4's repeated use of the phrase "a lot" reinforces the wide applicability of her claim that the anxious behaviour of these individuals influences their experience of breathlessness.

In summary, the structure and content of this second story effectively presented N4's circular argument that anxiety may be both the cause of acute breathlessness and the result of frightening dyspneic episodes. The story also highlighted the fact that it is anxious behaviour—the anxiety-dyspnea-anxiety cycle (Carriere-Kohlman et al., 1993)—that is confronted and managed by nurses caring for patients hospitalised during an acute exacerbation of their chronic pulmonary disease.

Case Example #9

N7 had practised as a registered nurse for five years working on a medical unit responsible for a variety of acutely ill patients including acutely ill COPD patients. She had received P7 as a patient from the emergency department the previous morning and had cared for her since her admission to the unit. P7's husband (CG7.1) had been present during the admission process. N7 suggested that he was very involved in his wife's care and was very anxious about the seriousness of her present illness. P7, a chronic smoker, had a long history of COPD and over the last two years had had frequent acute exacerbation events which had necessitated emergency hospitalisation. She was now essentially housebound because of her extreme breathlessness with any physical exertion.

I have included two linked stories from N7's interview in the following case example. They demonstrate this nurse's use of a COPD illness template both in the account of her management of this patient's care and in her explanation of the importance of emotional behaviour in a patient's experience of acute dyspnea. Although the stories were recounted in answer to different questions and were not told contiguously, both talk about the same event, P7's increased experience of dyspnea following use of the ensuite bathroom shortly after her admission to the in-patient unit.

In the first telling of this story N7 focuses on the P7's continued visible breathlessness following her admission to hospital. In the second N7 talks about this patient's emotional behaviour during this episode of increased dyspnea. In both stories N7 highlights the assessment strategies and interventions that she used to assist in the management of P7's acute distress. The stories, in part, reveal the implications of employing such a template in the management of patient care for both the patient and

nurse and the relevance of emotional behaviour of patients during episodes of breathlessness. The stories contain no reference to this patient's previous experience or management of prior acute exacerbation events:

N7: Admission Story

But she's still really...struggling for breath

Story Stimulus:

16 PAT: OK /So . do you know why she came to the hospital this time?

Abstract/Evaluation:

17 N7: Shortness of breath

Orientation/Evaluation:

17 /Uum her-she was having a cold for about a

18 week /Shortness of breath /Having trouble breathing /Ahm bit of a

19 cough /Heaviness

Complicating Action:

19 /So she came in /to emerg /I believe /...around

20 5:30 this morning with those complaints /And she had a lot of

21 Ventolin in emerg /Like 13 times /She had Ventolin and Atrovent in

22 saline

Evaluation:

22 /Bang bang bang /Right after each other

Orientation:

22 /[hh] An sh' I got here

23 about...um maybe 10 /around 10 o'clock

Complicating Action:

23 /She came up /had to go to

24 the bathroom /Then she got back to bed

Evaluation:

24 /Extremely short of breath

25 /Again

Resolution:

25 /So she had a Ventolin right away

Evaluation:

25 /O2 sats were 98 /They

26 were very good /But she had so much ox'-She had her oxygen and a

27 Ventolin mask going at that time /But they've been 97 at 3 litres⁴⁰ per

28 minute

Coda/Evaluation:

28 /But she's still really...struggling for breath

This first story was initiated by a question asking about N7's understanding of why P7 came to hospital on this specific occasion. In response, the problem addressed by N7 in this event-specific story was the unanticipated severity of P7's shortness of breath. The story events describe P7's complaints of increased dyspnea shortly after

⁴⁰ Oxygen is frequently delivered to patients by means of a nasal cannula. The flow of oxygen delivery is measured in litres per minute, i.e., 3 litres per minute (McKenry & Salerno, 1998; Smeltzer & Bare, 1996).

her admission to the nursing unit.

The story portrays a tension between this nurse's usual assessment and care of patients with increased dyspnea and her description of this patient's continued severe breathlessness behaviour. I will discuss this apparent tension, as identified in the first story, by examining in turn the story structure, content, and N7's use of rhetorical strategies. I will also address the analytic function of this story in relation to the use of a caregiving template by nurses responsible for patients with acute exacerbations of COPD.

The abstract and evaluation phrases at the beginning of the story imply that in the ensuing account N7 intended to explain P7's hospital admission within the context of her previous experience of patients admitted with "shortness of breath". The initial orientation phrases which follow the abstract include a description of factors which N7 presents as those events that either precipitated or simply preceded P7's admission. N7 does not talk of a precise causal event and, unlike the admission stories routinely told by patients and family caregivers, in her description of these events there is no sense of urgency or crisis.

Rather, she presents P7's week-long experience of a "cold" with a "minimal cough" accompanied by "shortness of breath" and "heaviness" (perhaps a reference to angina pain)—"having trouble breathing"—as simply the circumstances that occurred prior to P7's arrival at the hospital. These particular circumstances are offered without qualification or explanation, as though they are typical of usual events that could precede the admission of any COPD patient (part of the normal pattern for patients with an acute exacerbation of their COPD). It would seem that, although P7 had had a cold, the point being made by N7 is simply that this patient came to the emergency

phrase which interrupted the narrative phrases and separated the narrative clauses from the story resolution emphasised the central theme of the story, the unexplained seriousness of P7's difficult breathing. The repetition of the word "bang" describing the administration of bronchodilating drugs and the use of the intensifier "extremely" depicting P7's experience of dyspnea, clearly implied, even without knowledge of the usual administration regime of these medications, that this patient was very breathless:

21 Ventolin in emerg /Like 13 times /She had Ventolin and Atrovent in
22 saline /**Bang bang bang** /Right after each other

24 /Then she got back to bed /**Extremely** short of breath
25 /Again

In the final group of evaluation phrases at the conclusion of the story, N7 again used a part of the nurses' template in an attempt to understand the patient's distress. She suggested that with an oxygen saturation level of "98" or even "97", P7 should have been less breathless—"they [*the oxygen saturation levels*] were very good". The coda clearly contrasts the somewhat benign nature of the events that were described as having preceded and/or precipitated P7's admission to hospital and the observed breathless behaviour of P7 on the in-patient unit. The story concludes, as highlighted below, with a sense that N7 has been unable to adequately account for P7's behaviour using her usual illness template:

28 /But she's **still really**..struggling for breath

From N7's story, it seems that P7 required more medication than N7 expected and remained more breathless ("still really ..struggling for breath") than she thought she should, given her usual care and assessment. One way of accounting for this is to conclude that the template that N7 possessed, although utilised to account for P7's behaviour, predicted was apparently inadequate.

The second story about P7's increased dyspnea was told in answer to my question

about the care N7 usually provided for patients who "get into distress". Reference to the use of a caregiving template can again be identified. In addition, this story emphasises the nurse's actions with respect to P7's anxious behaviour during this dyspneic episode:

N7: Story of Nursing Care

She was relaxing /her breathing was getting easier

Story Stimulus:

57 PAT: What do you do when ah patients get into distress?

58 /Breathing problems?

Abstract/Generic Story:

59 N7: If they have a Ventolin or Atrovent order /we give it /or get

60 one /Listen to their lungs /Do O2 sats /Give oxygen /Calm them down

61 /Sit with them /Reassure them everything's alright

Re-orientation/Story Stimulus:

62 PAT: So you always stay with them for example? /Has she been /Has

63 that happened to her?

Orientation:

64 N7: When she first came in today /After they transferred her off the

65 stretcher an that

Complicating Action:

65 /An she had to go to the bathroom right away /So

66 then I sat with her /An took her saturations /An gave her her mask

67 /An you know /Just told her /"Just relax /You'll get through this"

Re-orientation/Story Stimulus:

68 PAT: So...what exactly would you say? /I'm really interested in that

69 N7: In what I'd say?

70 PAT: Yeah //Or what would you say to her?

Complicating Action:

71 N7: Uum]..I just reassured her

Orientation:

71 /I had the O2 sat monitor on

Complicating Action:

71 /"You

72 know they're 98 /they're good"

Orientation:

72 /An her husband was there

Evaluation:

72 /An he

73 needs just as much reassuring as she needed

74 PAT: He did?

75 N7: Yeah he was anxious too /"Well what are they" /an "She's really

76 bad" /an you know

Complicating Action:

76 /..Just sat with her /Made sure that /she kept her

77 mask on /An she was concentrating on /You know /Getting air an

78 breathing an

Evaluation/Resolution:

78 /She knew someone was there /So she was /You could

79 tell /She was relaxing /Her breathing was getting easier

In this second story based on P7's dyspneic episode after her admission to the in-patient unit, N7 expands on the events of the first telling by adding a description of the emotional care she gave to this patient. The total story is structured into three major sections: an initial generic story describing usual nursing care for patients in respiratory distress, an event-specific story of N7's care of her patient, and a third telling of the event-specific story. This structure reflects the initial question I asked to elicit a description of usual care and the subsequent questions interjected into the conversation in an attempt to understand more clearly N7's actual practice.

The first section, the abstract, a generic story told in response to my question regarding what she did when "patients get into distress", contained a list of physical and emotional interventions arranged in a hierarchical order of importance beginning with four physical/technical strategies and concluding with three emotional interventions. Although not explicitly stated, I would suggest that the structure of the list (number and order) implied that emotional care was viewed by N7 as an adjunct to the use of more technical interventions such as medication administration ("Ventolin or Atrovent") and oxygen therapy ("do O₂ sats /give oxygen"). I would also suggest that N7's inclusion of the third person "we" in the list of interventions immediately implied that the care she was describing was part of a shared COPD illness template. This care reflected the care any nurse with her experience would provide faced with a similar situation of acute respiratory distress. The three final phrases of this section describe forms of emotional care, strategies not talked of in the first telling of this story. The event-specific story that follows is then built around these approaches to emotional care.

The orientation phrases following N7's introductory generic story segment

indicated that N7 intended to use the events of the same story to explain further her usual care of COPD patients when they were distressed:

64 N7: When she first came in today /After they transferred her off the
65 stretcher an that

Although the question did not specifically refer to the patient's emotional reaction to dyspnea, N7's story focuses on this aspect of care. The narrative phrases which follow initially present essentially the same story. In this telling N7 again states that she had assessed P7's level of distress ("took her [oxygen] saturations") and administered appropriate medications ("gave her her mask"). She, however, expands the story by talking of the emotional support that she also provided. This psychological care included sitting with P7 and reassuring both the patient and her husband that everything would be "alright".

N7 then evaluates her care by comparing her assessment of the patient's respiratory status with what she would normally expect to see. Her measure of the patient's respiratory distress is reflected in the oxygen saturation levels. She states that P7's oxygen saturation levels were "good", and hence implies that she was justified in reassuring this patient that everything was going to be "alright". It is important to note, however, that the resolution of this second story contrasts with the resolution of the previous account. At the conclusion of the first story, P7 continued to be unusually breathless in spite of extra administration of inhalation therapy:

25 /O2 sats were 98 /They
26 were very good /But she had so much ox'-She had her oxygen and a
27 Ventolin mask going at that time /But they've been 97 at 3 litres per
28 minute /But she's still really..struggling for breath

In the second telling of the same story N7 adjusts the resolution of the narrative events by suggesting that the patient's condition actually improved following receipt of usual (appropriate) nursing care in the form of emotional support:

78 /she knew someone was there /so she was /you could
79 tell /she was relaxing /her breathing was getting easier

N7's story demonstrates her knowledge and use of a specific illness template in the management of an acute dyspneic episode. The template provided a repertoire of accepted caregiving strategies and potential explanations for both the patient's and the nurse's actions within given situations. When N7 told the story a second time she used another portion of her understanding of her COPD illness template to extend her explanation of a previously unreconcilable conclusion: i.e., a satisfactory oxygen saturation measurements and unusual dyspnea. In the second telling N7 introduces an additional strategy and expands the story to suggest that the respiratory distress had eventually been effectively managed.

Summary

Analysis of the above nurse stories illustrated the presence of a more or less shared COPD illness template in the nurses' talk of their work with these chronic pulmonary disease patients. This template defined both attributes and behaviours of hospitalised acutely ill COPD patients and the usual care provided by nurses working on in-patient hospital units. Their stories demonstrated that these nurses, like others in the study, used this illness template to interpret or account for both patient behaviour and nursing actions. According to Saylor (1995) illness categorisations, grouping of behaviours (symptoms) and attributes—what I have referred to as an illness template—are socially constructed models that develop over time. From Saylor's perspective, such structures are used by nurses to simplify and in some measure make manageable their caregiving tasks.

In the above stories the nurses demonstrated their use of the elements of a common

illness template. For example, they did not require patient-specific information about the factors that precipitated an acute event when caring for patients on an in-hospital unit. Their caregiving strategies were essentially based on elements of the pre-existing template: i.e., that these patients came to the hospital because they were "short of breath". As suggested this template also influenced the nurses' interpretation of the anxious behaviour that patients presented with when they were short of breath. For these participants this behaviour was invariably a cause of the patients' acute distress.

CHAPTER 10

DISCUSSION AND CONCLUSIONS

Chronic obstructive pulmonary disease (COPD) patients are frequently hospitalised because of acute exacerbation episodes of their chronic lung disease (Burns & Nicols, 1991; Burrows, 1985; Petty, 1985b). My interest in the needs of hospitalised COPD patients and family caregivers began several years ago when I practised as a bedside nurse in a medical-surgical intensive care unit. The patient group I cared for included patients and families during the crisis of acute exacerbation events of COPD which resulted in admission to the intensive care unit. My practice experience at the bedside and subsequent work as a nurse-researcher looking at the needs of family members of hospitalised patients (Rukholm et al., 1991, 1992) sensitised me to a gap in knowledge about patients' experience of acute exacerbation events necessitating hospitalisation. Although researchers acknowledge the difficulties in managing severe breathlessness, no studies to date have been done describing the experience of an acute exacerbation event from the perspective of patients, family caregivers, and nurses.

The purpose of this study therefore was to understand the complex event of an acute exacerbation of COPD from the perspective of patients, family caregivers, and nurses. My original intention was to describe this experience, and, using a qualitative inquiry approach, generate a theoretical understanding of the meaning of this event that could guide nurses in supporting COPD patients and their families. In this chapter I will provide a reminder of the background for this study as described in the literature review; expand on the utility of a narrative analysis approach in the examination of

interview data; draw conclusions from the meanings of the stories told by patients, family caregivers, and nurses; describe the potential implications of this new knowledge for nurses' care of patients and family caregivers; and address the implications of this work for future research.

I will argue that acute exacerbation episodes necessitating emergency hospitalisation are metonymic: that the understandings of acute episodes of dyspnea, as described in the participants' stories, reveal something about the experience of living with COPD as a chronic illness. I will also explore the value of understanding this chronic illness, characterised by acute exacerbation events, as a liminal experience replete with ambiguity. Finally, I will suggest that the stories told by these participants indicate that patients and family caregivers, and nurses, are largely unaware of each other's interpretation of these events and that these differing perspectives have important implications for nursing care and future research endeavours.

COPD as a Chronic Illness

One main theme revealed in the literature, as discussed in Chapter 2, was that functional capacity decreases steadily for individuals living with COPD. The documented components of the declining abilities experienced by individuals with chronic lung disease include a severe decrease in activity levels, as well as emotional and cognitive dysfunction, expressions of helplessness, anxiety, anger, feelings of depression and memory loss (Dudley et al., 1973, 1980; Gift et al., 1989; Gift & Cahill, 1989; Janson-Bjerklie et al., 1986; Leidy, 1995; Sexton & Munro, 1985, 1988).

Researchers claim, however, that a deterioration in lung capacity, as quantified by

present technology, does not necessarily reflect the functional capacity of COPD sufferers (Levin & Levin, 1993; Mahler et al., 1992). They suggest that understanding all aspects of the physical and emotional capacity of these patients is a much more complex problem than simply quantifying lung function parameters (Crockcroft & Heslop, 1996; Leidy, 1995; Mahler et al., 1992; Mahler & Wells, 1988). A review of COPD and family chronic illness literature suggested that families are central to the effective adjustment of chronically ill individuals to the challenges posed by COPD. In particular, it was recognised that families are intricately involved in the management of acute exacerbations of COPD (Barstow, 1974; Cossette & Léveques, 1993; Fagerhaugh, 1973; Sexton & Munroe, 1985). In my review of this literature, however, I was unable to locate a description of the experience of an acute exacerbation event from the perspective of the patients themselves. Although the preliminary work of DeVito (1990) and Simon and colleagues (1990) suggested how frightening acute episodes of dyspnea are for the sufferer, these studies do not describe the experience of an acute exacerbation event.

Chronic Illness and Families

Two main conceptual threads throughout the literature review informed the underlying structure for the research approach: chronic illness and family research. A number of theoretical models of chronic illness have been developed and, although little research has been done using these models, it was clear that they presented a way of understanding the complexity of the chronic illness experience. For this reason, as discussed in Chapter 3, Strauss and colleagues' (1984) construct of "managing medical crisis" was used as a framework for developing the interview schedule in this study.

Further, for the purposes of this study, a family was defined as any individuals who mutually identified themselves as family members (Gilgun et al., 1992; Johnson, 1998; Vaughan-Cole, 1998). There was an understanding that the family unit would provide such functions as caregiving during acute exacerbations. As discussed in Chapter 5, 10 patients were involved in the study along with 15 family caregivers and 10 nurses.

Analysis of Stories

The original aim of this study was to develop an understanding of this complex event from the perspective of patients, family caregivers, and nurses, and to present this understanding as research-based stories. As discussed in Chapter 4, a preliminary review of the qualitative literature suggested that participants frequently tell stories, within the context of research interviews, as they attempt to make sense of their world (Atkinson, 1992; Mattingly & Garro, 1994; Mishler, 1988). Using in-depth interviews as the main data gathering strategy, and based on the principles of ethnographic research, the study protocol therefore was designed to understand participants' stories. Narrative analysis, as a form of ethnographic inquiry, was adopted as a way of handling the textual data developed from the interviews.

Although narrative analysis is a relatively new extension within the qualitative paradigm, several models of story analysis have been described. Clear analytic guidelines, however, were not readily identifiable in the literature. Therefore, a systematic analysis protocol based on Labov and Waletzky's (1972) functional model and Agar and Hobbs' (1982, 1983) coherence model was developed to address the interview data. As described in Chapter 4, this strategy defined individual stories

(first- person event-specific, generic, and kernel stories) as the basic unit of analysis. Labov's (1972, 1982) method of parsing stories facilitated the identification of story events and meanings within these identified analysis units. Linked meanings across stories and interviews, using Agar and Hobbs' (1982, 1983) coherence strategy, formed a major component of the analysis process. Analysis was also informed by attention to discursive and rhetorical aspects of the stories. A full account of the analytic process was presented in Chapter 5.

The application of a form of narrative inquiry as a data analysis strategy resulted in the description of the events surrounding an acute exacerbation episode and the communication of the meanings of this experience not previously reported in the literature. The stories presented by the patients, family caregivers, and nurses were personal accounts of events of unusual dyspnea that conveyed the meaning of these experiences for the participants. The use of first-person event-specific stories, rhetorical devices such as the use of direct quotations, the storyteller frequently assuming the voice of the various participants, and word and phrase repetition, reinforced the persuasiveness of the accounts.

Participants told stories about events related to an acute exacerbation episode that included admission circumstances, causes of acute and chronic illness, nurse-patient interactions, and general circumstances of living with a chronic lung disease characterised by acute exacerbation events. Linked story meanings were also identified throughout the participants' accounts. As presented in Chapters 6 through 9, analysis of the linked meanings demonstrated that patients and family caregivers understood the events of acute episodes of dyspnea differently from nurses.

For example, when I examined the linked meanings, two major groups of stories

emerged: i.e., stories told by patients and family caregivers about the crisis of an acute exacerbation event and causes of acute and chronic illness; and stories related by nurses about the usual nursing care of patients during the patients' in-hospital stay, including their understanding of the relationship of anxiety and breathlessness. When describing acute exacerbation events, patients and family caregivers told stories about death, vulnerability, and causes of illness; nurses told stories describing a pattern of common patient and nurse behaviours that I labelled a COPD illness template. In the following section I will re-examine these new understandings of acute exacerbation events to further demonstrate how these meanings expand the knowledge of COPD illness and care.

Story Interpretations

In this segment of the discussion I will initially argue that the participants' understanding of the experience of acute episodes can be interpreted, in part, as a representation of the total experience of living with this chronic illness—a "part for whole metonymy" (Lakoff & Johnson, 1980; van der Geest, & Whyte, 1989). Based on an understanding of the metonymic function of acute exacerbation events, I will then examine the stories of acute episodes within the context of COPD as a chronic illness. I will interpret the events described by patients and family caregivers during acute exacerbation events as liminal or transitional experiences, "betwixt and between", and describe living with COPD as a liminal condition characterised by "blaming" and uncertainty or "ambiguity" (Frankenburg, 1986; Turner, 1967). Throughout this section of the discussion I will underscore the usefulness of a narrative approach in the development of a more complete understanding of COPD

illness and care.

Participant Stories: Part for the Whole

Metonymic meanings linking acute exacerbation events and the experience of COPD as a chronic illness were identified throughout the participants' stories. Although the interviews centered around the patients', family caregivers', and nurses' experiences of acute exacerbation episodes, the meanings identified situated the participants' understanding of these events within the context of their everyday experience of COPD as a chronic illness. An understanding of the broader experience of living with COPD as a chronic illness, the standing of part for the whole, can be identified in the watershed, vulnerability, causes of illness, and nurses' template stories.

Watershed stories. The patient's and family caregivers' understanding of the fear associated with living with COPD characterised by acute exacerbation events was identified in their death stories. As described in Chapter 6, patients and family caregivers told stories that talked about death. In these death stories (e.g., "*I thought he was a gonner*") participants described two kinds of dyspneic episodes: i.e., distinct moment in time when the patients or family caregivers thought that the patients had died (near-death story), and incidents where the patients feared that they were going to die or the family caregivers thought they might see family members die (shadow-of-death story). Both kinds of death stories had similar structure and content elements. The patients and family caregivers talked about the patients' uncontrollable dyspnea, the actions the patients or family caregivers initiated to obtain professional help, and the rescue or eventual outcome of the acute episodes.

The near-death and shadow-of-death stories are metonymic. As highlighted in Chapter 6, the near-death stories functioned as watershed events representing an unequivocal change in the patients' and family caregivers' understanding not only of acute exacerbation episodes, but also of the experience of living with chronic illness. Subsequent to a near-death event, patients and family caregivers, in shadow-of-death stories, talked of living with a sense of fear as they anticipated future acute exacerbations. All previous and subsequent acute dyspneic experiences were constructed in relation to this near-death event. Patients and family caregivers revealed themselves as living between acute events in the shadow of fear created by a particular acute episode.

Stories of vulnerability. Stories of the patients' perception of physical and emotional disability in relation to experiences of intractable dyspnea necessitating hospitalisation were described in Chapter 7. These stories reflected the subjective sense of vulnerability that these individuals also lived with on a daily basis. Common structure and content elements identified across the participants' vulnerability stories included narrative phrases describing dyspnea, narrative phrases outlining some form of physical or emotional disability, and resolution phrases recounting the outcome of the dyspneic event.

In physical vulnerability stories (e.g., "*When your lungs don't work your legs don't work*") patients and family caregivers conveyed how the presence of increasing dyspnea often made previously simple tasks such as walking and speaking impossible. These stories emphasised that an increased sense of breathlessness resulted in a reduction in physical activity during acute exacerbation events, and that on some occasions increased physical activity resulted in increased dyspnea, precipitating acute

exacerbation events. These accounts, however, also addressed the circular causal relationship between activity and breathlessness experienced by patients both on a daily basis and during acute events.

In emotional vulnerability stories (e.g., *"It's scary /when you can't breathe"*), as in the stories of physical vulnerability, the relationship between emotional actions and dyspnea was often circular. When analysing the data, as described in Chapter 7, it was sometimes difficult to determine whether the patient sensed increasing breathlessness and then became anxious or the reverse. In other stories the relationship between emotional disability and unusual breathlessness appeared to be more complex. Analysis of these stories demonstrated that persistent breathlessness was understood as a sign of intractable dyspnea necessitating an emergency admission to hospital rather than the cause of breathlessness. Although these stories were told in the context of an acute exacerbation event and the participants talked of the patients' conscious efforts to control their emotional behaviour during these acute episodes, their stories also reflected the patients' struggles with emotional disability on a daily basis.

Patients' and family caregivers' stories of physical and emotional disability gave concrete expression to the subjective invisible experience of unusual breathlessness. The participants' stories highlighted the ambiguity and uncertainty experienced by patients and family caregivers in their attempts to manage increasing breathlessness. In addition, through their descriptions of acute exacerbation events, patients and family caregivers made visible the subjective experience of shortness of breath with which these patients continually lived.

Causes of illness stories. Several participants, while describing the circumstances of a current acute exacerbation event, also provided accounts of how the patient had

developed their underlying chronic illness. These stories were coloured by a sense of uncertainty or ambiguity about the cause of the patients' illness and feelings of being victims of circumstances beyond their control. The patients' and family caregivers' stories describing circumstances/causes related to both acute or chronic lung disease (e.g., *"Sure I've smoked all my life /but I also put in 37 years at the Mine"*) were examined in Chapter 8. In the context of questions related to an acute exacerbation event both patients and family caregivers told a number of stories about the causes of both aspects of the patients' illness.

Although the stories concerning the onset of chronic lung disease described a long history of smoking behaviour, patients and family caregivers alike, nevertheless, consistently provided alternate explanations for the patients' chronic illness. Their stories highlighted emergency hospital admissions because of acute respiratory illness and the patients' previous home and work environment—living and working in a specific mining community, an area with a history of longstanding industrial pollution.

In relation to the causes and circumstances surrounding acute exacerbation events, patients and family caregivers often indicated that, although they knew *when* the patient was acutely ill, they were much less sure of *what* precipitated acute exacerbation events. In stories describing the clues or signs of acute illness, they talked of the patient-specific behaviours that signalled the presence of acute illness. These accounts functioned to highlight the imprecision of the participants' stories in relation to the causes of acute and chronic illness. As demonstrated, the stories of the causes of chronic ill health and acute illness were linked. Through these stories patients and family caregivers stated or implied that the patients were responsible, at least in part, for both their chronic lung disease and acute exacerbation events.

Template stories. The nurses in their stories of acute exacerbation events compared the behaviours of patients admitted with an acute exacerbation of COPD with the usual behaviours of patients who suffered from COPD. Their stories, examined in Chapter 9 (e.g., "*COPD's are your most anxious people*"), included accounts about admission circumstances, causes of illness, nurse-patient interactions, and general circumstances of living with a chronic lung disease characterised by acute exacerbation events. Most nurse stories, however, focused on the nurses' care of patients hospitalised with an acute exacerbation of COPD rather than the circumstances preceding or precipitating the patients' hospital admission. Specifically, these stories talked primarily of the nurses' physical and emotional care of patients on the in-patient unit, the patients' emotional behaviour during an acute exacerbation event, and a pattern or template of usual patient behaviours and nurse caregiving actions.

In contrast to the patients' and family caregivers' accounts, the nurses' stories did not reflect the patient's hospital admission as a crisis or emergency, but rather implied that this group of patients came to the hospital simply because "they were short of breath". In addition, the nurses' stories highlighted the patients' emotional reactions and breathlessness rather than the shortness of breath itself. Further, an examination of the nurses' stories revealed a pattern of behaviours and expectations that was shared by these nurses—what I described in terms of a more general COPD illness template. The nurses' stories illustrated that this common template was used by these nurses both to explain patients' illness behaviour in general and to account for the nurses' caregiving actions.

In summary, all participants interpreted acute episodes of dyspnea metonymically within the context of the patients', family caregivers', and nurses' experience of

COPD as a chronic illness. Patients' and family caregivers' near-death stories illustrated the threat of death (shadow) under which these participants lived. The physical and emotional disability described by patients during acute episodes of dyspnea in the patients' and family caregivers' vulnerability stories, represented the patients' acute and on going experience of disability. The uncertainty and blaming expressed in the patients' and family caregivers' acute exacerbation accounts were mirrored in their stories of causes of illness. Finally, the nurses' stories describing their work with hospitalised COPD patients presented a common understanding of the patients' illness behaviour for both acute and chronic illness situations.

Although the initial intention of the study was to understand acute exacerbation events as a part of the patients' chronic illness, examination of the participants' stories indicate that these episodes cannot be understood without taking account of the experience of living with chronic lung disease. Analysis of the patients', family caregivers', and nurses' perceptions of acute exacerbation episodes sheds light on their understanding of both acute illness events and the wider experience of COPD as a chronic illness.

Therefore, to further understand the participants' interpretations of the specific events of acute illness and the contribution of this knowledge to the care of COPD patients, it is necessary to employ, in addition to Strauss and colleagues' (1984) concept of medical emergency, another explanatory model that considers acute exacerbation events within the context of the overall experience of living with COPD. In the following section I will interpret the events described by patients and family caregivers within the context of COPD as a chronic illness and liminal experience.

COPD: A Liminal Experience

Victor Turner (1967), an anthropologist, studied the ritualistic behaviour of Ndembu society in Northern Rhodesia (now Zambia) and described his understanding of transitional life events using a model of liminality. This liminal model is based on the concepts of transition, ambiguity, and marginalisation, and has been adapted for use by other social scientists in their attempt to understand a variety of sociological and illness situations (Bettis, 1996; Catron, Chiriboga, & Krystal, 1980; Fulton & Anderson, 1992; Mascia-Less, Sharpe, & Cohen, 1987). More specifically, two groups of medical anthropologists (Frankenberg, 1986; Monks & Frankenberg, 1990; Murphy et al., 1988) have employed Turner's model of liminality to assist in their interpretation of various aspects of chronic illness.

Monks and Frankenberg (1990) used an adaptation of Turner's model in their analysis of the life stories and illness narratives of individuals with multiple sclerosis. They contend that individuals with this chronic illness experience "liminal phases within [emphasis in original] the course of disablement" (p. 49). These authors describe the eventual assignment of a multiple sclerosis diagnosis as a liminal experience that identifies the boundaries of the patients' illness and changes the patients' understanding of their illness:

The diagnosis [of MS] was an event which effectively separated and characterised the prior problematic period from the equally problematic, but qualitatively different, period which succeed[ed] it. (Monks & Frankenberg, 1990, p. 6)

Murphy and colleagues (1988), also medical anthropologists, used the model of liminality in a somewhat different and broader sense. In their work with individuals who became physically disabled as a result of accident or disease, these researchers conceptualised living with a chronic illness as a liminal experience. From their

perspective, the chronically ill individual, once diagnosed, lives in a transitional state "betwixt and between" (Turner, 1967, p. 93) their prior health and ultimate death (Murphy et al., 1986). The chronic illness experience of protracted transition experienced by the physically disabled, a liminal condition characterised by clear boundaries (health and disability), is also fraught with marginalisation and ambiguity: i.e., the individual is between health and death; the major symptoms experienced by patients are subjective and more or less ambiguous or invisible; and patients are subject to stigmatisation or marginalisation.

Interpreting the experience of acute exacerbation events using a liminal perspective facilitates an examination of the participants' stories within the context of COPD as a chronic illness. The application of this model both allows episodes of unusual breathlessness to be understood as liminal events, and allows the chronic illness of COPD to be interpreted as an experience containing liminal periods. The experience of acute exacerbation events, the part, is reframed within the entire experience of living with COPD, the whole. In the following discussion acute exacerbation events described by the participants will be interpreted in three ways: as transitional events, "betwixt and between" health and death; as situations of marginalisation, involving the "attribution of blame"; and as "experiences of ambiguity", representing the invisible experience of dyspnea.

"Betwixt and Between"

By definition, a liminal or transitional state/event has identifiable boundaries (Frankenberg, 1986; Turner, 1967). In this study patients and family caregivers defined the boundaries of the COPD chronic illness experience within the context of

a particular acute exacerbation episode. The near-death or watershed stories told by patients and their family caregivers implied that these participants identified the events of a particular acute exacerbation episode as the start of the patients' chronic illness as they now understood it.

The experiences recounted, although about a specific acute exacerbation event, marked dramatically the beginning of the patients' chronic illness. They described it as a threshold from which, through experience, they now knew "...there [was] no way back" (Frankenberg, 1986, p. 616). For several patients and family caregivers a specific near-death event also portrayed death as the other boundary of this otherwise ambiguous, liminal state. In their stories the patients and family caregivers talked of their recognition that the patient would die during an episode of intractable breathlessness.

Attribution of Blame

The liminal quality of COPD as a chronic illness was also evident in the patients', family caregivers', and nurses' stories of the causes of both chronic lung disease and acute exacerbation events. Individuals in liminal circumstances are often blamed for and marginalised because of their circumstances. Chronically ill patients by definition are often understood as outside of the main illness group, the acutely ill, in part, both because of the long-term nature of their illness and because they are in some way blamed or held responsible for their illness (Mascia-Lees et al., 1987; Murphy et al., 1988).

Although, patients and family caregivers, in the stories of the causes of illness, frequently portrayed COPD sufferers as victims of circumstances beyond their control

(e.g., poor air quality), they also blamed the patients for their illness by acknowledging the patients' smoking behaviour as a contributing factor to both chronic lung disease and acute dyspneic episodes. The nurses also blamed patients for their acute, and by extension, their chronic illness. In stories of usual care the nurses portrayed the patients' anxiety related behaviours as an important contributing factor in the initiation of acute exacerbation events. This attribution of blame illustrates the utility of interpreting COPD and an acute dyspneic episode as liminal conditions characterised by marginalisation.

Experiences of Ambiguity

Finally, the experience of chronic illness for COPD patients between the boundaries of a near-death event and death itself was further outlined in patients' and family caregivers' stories of physical and emotional disability. These stories described the unclear relationship between the patients' dyspnea and their physical and emotional functioning. The stories were characterised by liminality (ambiguity or uncertainty) represented, in part, as a perception of physical and emotional vulnerability. The patients and family caregivers, through their stories, consistently tried to make visible and hence legitimise (Murphy et al., 1988) the patient's otherwise invisible breathlessness, the characteristic which most commonly defines COPD as a chronic debilitating illness.

Their poignant stories of physical and emotional disability illustrated that in contrast to the clarity of the beginning (a near-death event) and ultimate end of their chronic illness (death), the actual course of the COPD chronic illness experience, characterised by acute exacerbation events, was not as clearly described. The

participants' stories, nevertheless, gave structure to the ambiguous events that constituted acute exacerbation events and that linked acute illness with the experience of living with COPD. In these situations of ambiguity the participants' stories connected the particular (acute exacerbation events) with the broader experience (living with COPD). Through their accounts, the patients in this study who were "permanently sick" (Frankenberg, 1986) (i.e., suffering from a chronic illness) provided a representation of COPD as a liminal condition also characterised by ambiguity.

In their stories, nurses talked of their usual work with patients hospitalised because of an acute exacerbation event. Although the experiences described were substantively different from those presented by patients and family caregivers, a sense of liminality was also identified in the nurses' accounts. In their management of the patients' anxiety and breathlessness on the in-patient unit, the nurses spoke of an ambiguous relationship between the patients' presenting anxious behaviour and complaints of breathlessness, or the "anxiety-dyspnea-anxiety cycle" (Carriere-Kohlman et al., 1993). I have interpreted their talk of the use of a shared pattern of care ("a common COPD illness template") in their work with patients during these acute events, as an attempt by these participants to place structure on this liminal (ambiguous) experience.

Further, as discussed in the story chapters (Chapters 6 through 9), all participants included a kind of conjectural knowledge in their storytelling when they talked of the subjective experience of intractable dyspnea necessitating emergency hospitalisation. Ginzburg (1990) describes it as a kind of knowledge only gained through experience:

The ability to tell an unhealthy horse from the state of its hooves, a storm coming up from a shift in the wind, or unfriendly intentions from the shadow in someone's expression would certainly not be learned from treatises on the care of horses, or on weather, or on psychology. In each case these kinds of knowledge were richer than any written authority on the subject: they had been learned not from books but from listening, from doing, from watching; their subtleties could scarcely be given formal expression and they might not even be reducible to words; they were the heritage—partly common and partly split—of men and women in any class. A fine common thread connected them; they were all born of experience, of the concrete and the individual. (pp. 263-264)

Patients, family caregivers, and nurses spoke of signs or clues of intractable dyspnea associated with acute exacerbation events in their near-death, vulnerability, causes of illness, and usual care of hospitalised patient stories. The warrant for these signs as evidence of the patients', family caregivers' and nurses' claims concerning the patients' illness were as unique and elusive as those described above by Ginzburg (1990). The participants' stories demonstrated that the signs they described had been learned as a result of the participants' experiences of acute exacerbation events.

The signs of or clues to the patients' perception of physical vulnerability were diverse: e.g., keeping a gun beside the chair for protection, being unable to walk a block, or the inability to comb one's hair. As Ginzburg (1990) suggests, on occasion, "their subtleties [*of these clues or signs*] could scarcely be given formal expression" (p. 264). The signs or clues that represented emotional vulnerability were more ambiguous and elusive than those describing the patients' defense of physical vulnerability: e.g., crying because of lost papers or the being unable to sit in a room full of people. These stories acted as proxies for the formal expression of the patients' experience of illness.

In summary, although these participants told different stories about their experiences of chronic lung disease within the context of an acute exacerbation event

necessitating hospitalisation, an enhanced understanding of their shared meanings of these experiences is obtained when the stories are interpreted within Turner's model of liminality. For example, analysis of the patients' and family caregivers' death stories revealed that the boundaries of the patients' chronic illness experience were defined by the participants' interpretation of the liminal experience of a near-death acute exacerbation event. Their stories of acute illness and the shadow between acute events under which these individuals lived, described the betwixt and between connecting the patients' prior health and their ultimate death.

The blaming behaviour described in the patients', family caregivers', and nurses' acute exacerbation accounts is similar to the culpability ascribed to individuals with physical disability described by Murphy and colleagues (1988). COPD sufferers, family caregivers and nurses indicated that patients were at least in part responsible for both their acute and chronic illness. This attribution of blame was part of the patients' and their family caregivers' experience of acute exacerbation events and of living with COPD as a chronic illness. The incapacitating disability described in the physical and emotional vulnerability stories highlighted the ambiguity or uncertainty with which the participants lived. Finally, the patients', family caregivers', and nurses' stories portrayed the invisibility of dyspnea. The signs used by these participants reinforced the ambiguity of acute and chronic illness situations.

Conclusions

In conclusion, the analysis presented in this thesis of the stories told by participants provides important understandings of both the experience of an acute exacerbation episode and of living with COPD as a chronic illness. The use of a narrative approach

gave access to the personal perceptions of patients, family caregivers, and nurses: stories of patients hospitalised during an acute exacerbation event, of family caregivers supporting the patient during their acute illnesses, and of nurses caring for these patients on the in-hospital units. As a result of the analysis process, it was clear that patients and family caregivers described the events and meanings of acute episodes differently than nurses working on in-hospital units. Patients and family caregivers talked of the immediate and long-term effects of acute exacerbations events. In contrast, nurses focused on their work with patients on the in-patient unit and consistently anxious behaviours of hospitalised COPD patients.

It was apparent that for patients and family caregivers near-death episodes functioned as watershed events. These particular acute illness episodes marked the beginning of the patients' and family caregivers' recognition of the patients' chronic lung disease and foreshadowed their eventual death. Patients and family caregivers presented their perception that patients *know* when they are acutely ill and require emergency care. As described in the physical and emotional vulnerability stories, patients and their family caregivers had limited strategies to manage these situations at home. They confirmed that they considered emergency hospital admission as a fortuitous resolution to episodes of uncontrollable dyspnea. The patients' and family caregivers' stories also supported and extended previous research findings regarding the importance of family caregivers' involvement in the patients' care during acute exacerbation events, in part, by describing the family caregivers help-seeking behaviour.

Analysis of the nurses' stories describing their work with patients on the in-hospital unit, confirmed that the nurses' perceptions of acute exacerbation events

differed from those of patients and family caregivers. The nurses' stories frequently focused on the contribution of anxiety to the patients' experiences of acute dyspnea. In contrast to the patients' and family caregivers' perceptions, the nurses presented anxiety as a primary cause of acute respiratory distress and were essentially unaware of the patients' and family caregivers' understanding of the causes of acute exacerbations events.

The stories told by patients, family caregivers, and nurses are metonymic. In describing acute exacerbations episodes of COPD, they provided an understanding of the experience of COPD as a chronic illness. The stories also demonstrated that living with COPD, a chronic condition characterised by acute exacerbation events is a liminal experience. It is a condition betwixt and between health and death, associated with marginalisation and blaming, and marked by ambiguity and uncertainty.

Finally, the stories identified in this study functioned to demonstrate the pattern of illness experienced by COPD patients and their family caregivers. Through the analytic process of examining individual participants stories, I have demonstrated that acute exacerbation events are part of the entire experience of living with COPD. The meanings presented by participants suggest that acute exacerbation events are part of a much larger whole, the larger process of an illness-towards-death experience. The story meanings also demonstrate that health care in hospital is incomplete insofar as nurses are unaware of the understandings of these episodes from the perspective of the patients and family caregivers.

Implications

Now I will suggest how these understandings can assist nurses in their care of

COPD patients and outline directions for future research.

Nursing care. The care of patients hospitalised for acute respiratory distress presents challenges for nurses working on in-patient hospital units. This study, describing the understandings of patients', family caregivers', and nurses' of acute exacerbations of COPD, provides important insights which could assist nurses in their care of these individuals. For example, the recognition that acute exacerbation events, as described in death, vulnerability, causes of illness, and nurse template stories, act as a metonym for the participants' experiences of living with COPD, suggests that episodes of acute illness necessitating hospitalisation cannot be understood in isolation from the participants' broader experience of chronic illness.

Moreover, patients' and family caregivers' experiences of near-death events influenced their understanding and management of both COPD as a chronic illness and acute exacerbation episodes necessitating hospitalisation. The near-death and shadow of death stories highlighted the fear and distress experienced by both patients and family caregivers during these acute events. It is clear that the experience of a near-death event influenced the patients' and family caregivers' interpretation of the seriousness of future uncontrollable dyspneic episodes.

Further, the stories of physical and emotional vulnerability, describing the events and behaviours that patients and family caregivers recognise as signs of acute respiratory distress, provide behavioral examples for nurses of the participants' understandings of "invisible" breathlessness in situations of acute respiratory distress. An understanding of the meaning and function of these perceptions would assist nurses in understanding the ambiguity experienced by patients and family caregivers during, and in anticipation of, these frightening episodes. Hence, I would suggest that, during

episodes of acute illness, nurses must have knowledge of the specifics of previous acute exacerbation admissions and, in the course of their care, seek to determine the impact of these events on individual patient's and family caregivers' perceptions of acute illness. This process would facilitate nurses' assessment of patient behaviour and their subsequent development of appropriate plans of care.

Furthermore, as anticipated, patients' and family caregivers' stories generally addressed different aspects of acute exacerbation events than the stories told by nurses. One difference centered around the "anxiety-dyspnea-anxiety cycle" (Carriere-Kohlman et al., 1993). Both patients, family caregivers, and nurses talked of the patients' anxiety during acute episodes of breathlessness. For patients and family caregivers, anxious behaviour was often presented as the *sign* or indicator of unusual dyspnea as well as a cause of acute respiratory distress. In contrast, this same anxious behaviour was consistently characterised by nurses, in their COPD illness template, as a *cause* of dyspnea. Its occurrence was used, in part, to account for the severity of the patient's increasing breathlessness.

It is important that nurses recognise the alternate meaning of anxiety for patients in acute respiratory distress. In work with acutely ill asthmatic patients, Janson-Bjerklie and colleagues (1992) suggested that individuals who became highly anxious during episodes of acute distress were correct in their assessment of illness requiring emergency hospitalisation. In the absence of clear objective measures of illness severity, the insights uncovered in this study suggest that anxiety may provide an important indicator of the COPD patients' actual illness severity and assist nurses in determining the care that patients require.

Future research. This study demonstrates the value of using a narrative approach

in the development of a description and an understanding of acute exacerbation events of COPD from the perspective of patients, family caregivers, and nurses. The presentation of intact participant stories, "primary data", has facilitated the demonstration of the trustworthiness of the interpretations of the textual interview data and enables judgments to be made regarding the generalisability of the identified linked story meanings or themes to other groups of chronically ill patients, family caregivers, and nurses (Riessman, 1993).

It can be argued from this study that a narrative approach is an effective strategy for uncovering meaning in in-depth interviews. Additional research in at least two areas would provide a more complete understanding of acute exacerbation events and the experience of patients and families living with COPD. Nurses and physicians working in the emergency departments are routinely involved in the care of patients and their family caregivers during acute exacerbation events necessitating hospitalisation. A study focusing on these individuals who interact with patients and family caregivers when the patient is in acute distress would provide descriptions of other important parts of this acute event. Their stories would enhance understanding of the patients' behaviour on admission to the emergency department and facilitate a description of the process used by physicians in determining the severity of an acute exacerbation event.

Given the metonymic relationship between acute episodes of dyspnea and COPD as a chronic illness, an understanding of acute exacerbation events (and by extension, the experience of living with COPD as a chronic illness), would also be enhanced by talking to patients and family caregivers outside the hospital environment between episodes of acute distress. The inclusion of patients who had participated in a formal

rehabilitation program would also assist in developing a more complete understanding of this illness experience.

CHAPTER 11

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APPENDIX A: TABLES

TABLE 1
Dyspnea: Review Articles from 1981 - 1990

Author/s	Date	Title	Discipline	Content of Review
Altose	1985	"Assessment and management of breathlessness"	Medicine	<ul style="list-style-type: none"> • definition of dyspnea • physiological mechanisms • psychological mechanisms • assessment of dyspnea • management of dyspnea
Burki	1987	"Dyspnea"	Medicine	<ul style="list-style-type: none"> • definition of dyspnea • physiological mechanisms • psychological mechanisms • assessment of dyspnea • management of dyspnea
Campbell & Guz	1981	"Breathlessness"	Medicine	<ul style="list-style-type: none"> • definition of dyspnea • physiological mechanisms
Carrieri et al.	1984	"The sensation of dyspnea: A review"	Nursing	<ul style="list-style-type: none"> • definition of dyspnea • physiological mechanisms • psychological mechanisms • assessment of dyspnea • management of dyspnea • implications for nursing
Gift	1990	"Dyspnea"	Nursing	<ul style="list-style-type: none"> • definition of dyspnea • physiological mechanisms • psychological mechanisms • assessment of dyspnea • management of dyspnea • nursing management
Killian & Campell	1985	"Dyspnea"	Medicine	<ul style="list-style-type: none"> • definition of dyspnea • physiological mechanisms
Lareau & Larson	1987	"Ineffective breathing pattern related to airflow limitation"	Nursing	<ul style="list-style-type: none"> • definition of dyspnea • physiological mechanisms • assessment of dyspnea • nursing management
Schwartzstein et al.	1990	"Dyspnea: A sensory experience"	Medicine	<ul style="list-style-type: none"> • definition of dyspnea • language of dyspnea • physiological mechanisms
Tobin	1990	"Dyspnea pathophysiological basis, clinical presentation, management"	Medicine	<ul style="list-style-type: none"> • definition of dyspnea • language of dyspnea • pathophysiology of dyspnea • dyspnea in the clinical setting • management of dyspnea

TABLE 2
Description of Family Units

Family#	Gender	Age	Marital Status	Living Arrangement	Admission Diagnosis	# Acute Admissions	Interviews Conducted
Family 3	Male	88	Married	Wife	Exacerbation COPD	> 3 over 5 years	Patient Nurse Wife
Family 4	Male	65	Widower	Alone	Exacerbation COPD	> 3 within last year /required ventilation	Patient Nurse Son
Family 5	Male	66	Widower	Alone	Exacerbation COPD/Emphysema	> 3 within last year /required ventilation	Patient Nurse 2 Daughters
Family 6	Female	60	Married	Husband/Grandson	Exacerbation COPD	> 3 within last year	Patient Nurse
Family 7	Female	70	Married	Husband/Son	Exacerbation COPD	> 3 within last year	Patient Nurse Husband Son Daughter
Family 8	Male	79	Married	Wife	Exacerbation COPD	> 3 within last year	Patient Nurse Wife Son
Family 9	Female	69	Widow	Daughter/Son-in-law [Granny Flat]	Exacerbation COPD	> 3 within last year	Patient Nurse 2 Daughters
Family 10	Male	73	Widower	Daughter [Main Floor Apartment House]	Exacerbation COPD	> 3 within last year	Patient Nurse Daughter Grandson
Family 11	Male	67	Married	Wife	Acute Asthma/COPD	> 3 within last year	Patient Nurse Wife
Family 12	Male	74	Married	Wife/Daughter	Exacerbation COPD /Severe Emphysema	> 3 within last year	Patient Nurse Wife Daughter

Note: > 3 = more than three acute exacerbation events that necessitated emergency hospitalisation.

TABLE 3
Transcription Conventions

Symbols	Meaning
1. Participants	
P	Patient
CG	Caregiver (Family)
N	Nurse
2. Phrases	
/	Used to indicate phrase boundaries
.	A one second pause between utterances
//	Indicates the beginning of an overlap in speaking turns
]	Indicates the end of an overlap in speaking turns
3. Audible breathing	
[-h]	In breaths
[h]	Out breaths
4. Intonation	
CAPITAL LETTERS	Marks an increased in the voice tone relative to previous talk
5. Gestures/Clarifying Information	
<i>[italics]</i>	Gestures used by the participants and explanatory information are included in italics in square brackets

TABLE 4
Study Participants by Story Genre

Families	Story Genre			Total
	First-Person Event-Specific	Generic	Kernel	
Unit 3: P3	8	-	-	8
CG3.1	9	1	-	10
N3	5	1	1	7
Unit 4: P4	8	1	2	11
CG4.1	5	7	1	13
N4	1	7	5	13
Unit 5: P5	20	3	3	26
CG5.1	7	16	2	25
CG5.2	14	15	2	31
N5	3	1	5	9
Unit 6: P6	14	5	4	23
N6	2	2	3	7
Unit 7: P7	8	5	-	13
CG7.1	13	1	-	14
CG7.2	4	6	-	10
N7	6	4	-	10
Unit 8: P8	5	7	5	17
CG8.1	8	6	4	18
CG8.2	6	6	-	12
N8	6	5	-	11
Unit 9: P9	3	5	6	14
CG9.1	16	2	1	19
CG9.2	9	11	3	23
N9	2	1	3	6
Unit 10: P10	9	6	3	18
CG10.1	4	4	2	10
CG10.2	12	9	2	23
N10	7	1	-	8
Unit 11: P11	10	6	3	19
CG11.1	9	2	4	15
N11	6	7	-	13
Unit 12: P12	9	2	3	14
CG12.1	10	3	-	13
CG12.2	7	7	1	15
N12	3	1	1	5
Total	268	166	69	503

TABLE 5
Study Participants by Story Events

Families	Story Event			
	Admission	Nurse-Patient	Causes of Illness	Other
Unit 3: P3	5	2	1	1
CG3.1	6	1	1	2
N3	3	1	1	-
Unit 4: P4	3	4	-	4
CG4.1	2	-	10	1
N4	4	-	2	6
Unit 5: P5	10	8	8	-
CG5.1	10	8	4	3
CG5.2	12	10	2	7
N5	-	4	3	2
Unit 6: P6	13	5	3	2
N6	4	-	3	-
Unit 7: P7	7	4	2	-
CG7.1	10	-	-	3
CG7.2	3	-	4	3
N7	2	3	-	5
Unit 8: P8	3	2	2	10
CG8.1	13	-	3	2
CG8.2	8	1	1	2
N8	6	-	-	5
Unit 9: P9	9	-	-	5
CG9.1	12	1	1	5
CG9.2	10	3	1	9
N9	2	-	1	3
Unit 10: P10	5	-	2	11
CG10.1	6	-	3	1
CG10.2	13	-	-	9
N10	2	1	3	2
Unit 11: P11	13	1	2	3
CG11.1	10	-	2	3
N11	5	5	-	3
Unit 12: P12	8	-	1	5
CG12.1	8	-	-	5
CG12.2	8	-	-	7
N12	1	-	-	4
Total	236	64	66	133

TABLE 6
Study Participants by Linked Story Meanings

		Meaning Category					
		Patient and Family Caregivers				Nurses	
		Death		Vulnerability		Causes of Illness	Template
Families		Near Death	Shadow of Death	Physical	Emotional		
Unit 3:	P3	-	-	3	2	-	-
	CG3.1	-	-	4	2	1	-
	N3	-	-	1	-	2	4
Unit 4:	P4	1	3	3	3	1	-
	CG4.1	-	1	1	-	7	-
	N4	-	-	5	-	-	7
Unit 5:	P5	1	3	5	4	12	-
	CG5.1	-	4	1	15	5	8
	CG5.2	1	3	2	17	7	-
	N5	-	-	-	-	-	8
Unit 6:	P6	-	-	4	12	7	-
	N6	-	-	-	-	2	3
Unit 7:	P7	1	4	1	4	-	-
	CG7.1	3	4	1	3	3	-
	CG7.2	-	-	-	8	2	-
	N7	-	-	1	-	1	3
Unit 8:	P8	1	1	4	9	1	-
	CG8.1	-	3	1	10	4	-
	CG8.2	-	1	3	1	3	-
	N8	-	-	-	-	2	9
Unit 9:	P9	-	1	6	6	-	-
	CG9.1	-	2	-	11	3	-
	CG9.2	1	1	-	11	5	-
	N9	-	-	-	-	1	4
Unit 10:	P10	2	1	3	5	7	-
	CG10.1	-	-	1	5	2	-
	CG10.2	-	3	2	13	5	-
	N10	-	-	2	1	2	3
Unit 11	P11	1	4	5	2	4	-
	CG11.1	1	4	2	3	3	-
	N11	-	-	-	1	1	11
Unit 12	P12	2	1	4	4	3	-
	CG12.1	2	3	3	2	3	-
	CG12.2	-	6	3	2	3	-
	N12	-	-	-	-	4	1
Total		17	65	83	145	102	53

TABLE 7
Interview Guide

Potential Questions Adapted from Strauss et al. "Managing of Medical Crisis"	
Reading Signs	<ul style="list-style-type: none"> • Tell me about how you/the patient got sick this time • Is this like other times?
Organising for the crisis	<ul style="list-style-type: none"> • What did you patient/family caregiver do? • Is this what you normally do?
Break down of organisation, potential and actual	<ul style="list-style-type: none"> • Why did you come to the hospital? • How did you decide to come to the hospital? • Who decided to come to the hospital? • Tell me about coming to the hospital.
Ceding responsibility to the hospital	<ul style="list-style-type: none"> • Tell me what happened when you got to the hospital. • Tell me of the nurses' care of you [the patient/family member].

APPENDIX B: ETHICS DOCUMENTATION

Ethics Committee Laurentian University

Laurentian University

Ramsey Lake Road
Sudbury, Ontario
Canada P3E 2C6
(705) 675-1151, ext. 3204

Université Laurentienne

Chemin du lac Ramsey
Sudbury (Ontario)
Canada P3E 2C6
(705) 675-1151, poste 3204



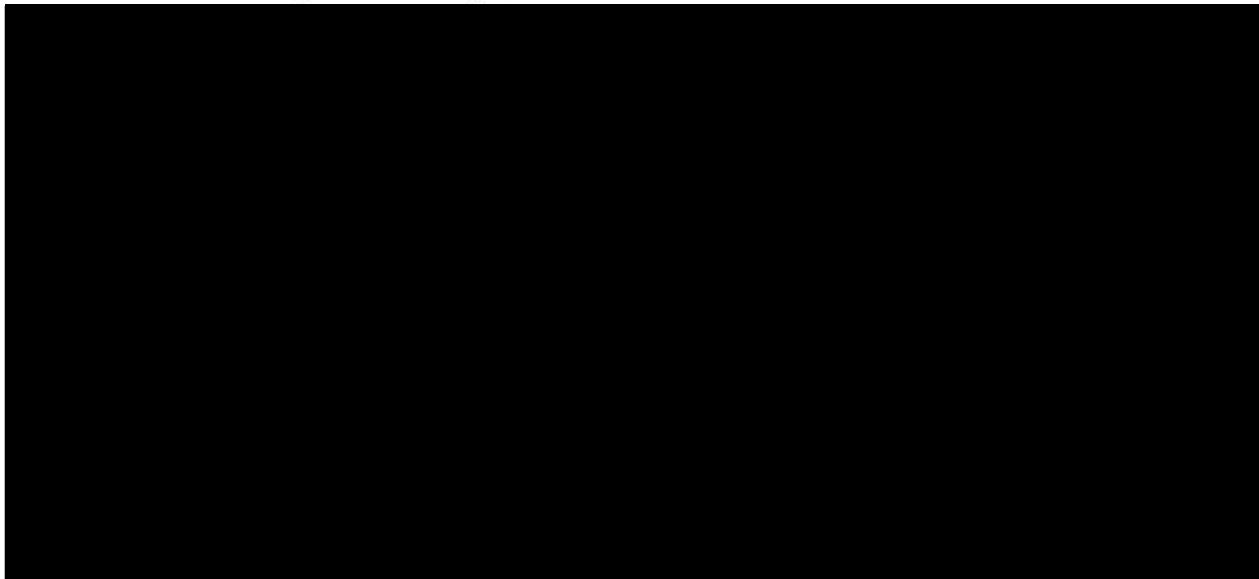
School of Graduate Studies
and Research
École des études supérieures
et de la recherche

This is to certify that the research proposal entitled Understanding an Acute Episode of Chronic Lung Disease from the Perspective of the Family and Nurse Caregivers, (1995-07-01)

Submitted by Patricia H. Bailey

has passed an Ethics review by the Laurentian University committee for the evaluation of

Research involving Human Subjects



Note: this approval covers only the documents submitted, in the language in which they have been submitted. Any changes to questionnaires or procedures must be re-submitted to the Committee, as stated on the form.

BUSINESS MINUTES Date: October 11, 1995 *Bioethics Committee* Page 4

Understanding An Acute Episode of Chronic Lung Disease From the Perspective of the Family and Nurse Caregivers

This research proposal will focus on patients, family and nurse caregivers on patients diagnosed with chronic lung disease. It was determined that there are no risks involved. The benefits obtained from this project will improve patient care.

It was moved by Dr. Shine and seconded by Dr. Grosso that

MOTION: *The Bioethics Committee recommends that the research proposal "Understanding an Acute Episode of Chronic Lung Disease from the Perspective of the Family and Nurse Caregivers", submitted by Pat Bailey, Ph.D. candidate, Laurentian University be accepted.*

Carried.

This acceptance will be communicated to Ms. Sonia Peczeniuk, Assistant Executive Director - Nursing.

Ethics Committee Sudbury Memorial Hospital



ESKO VAINIO, M.H.A.
EXECUTIVE DIRECTOR

SUDBURY MEMORIAL HOSPITAL
865 REGENT STREET SOUTH, SUDBURY, ONTARIO P3E 3Y9
PHONE (705) 671-5604 FAX (705) 671-5656



6 October 1995

Mrs. Pat Bailey
Laurentian University
School of Nursing
Ramsey Lake Road
Sudbury, Ont. P3E 2C6

Dear Pat:

The Ethics Committee considered your presentation and the material submitted regarding the nursing project entitled, "Understanding an Acute Episode of Chronic Lung Disease from the Perspective of the Family and Nurse Caregivers".

The Ethics Committee approved the following motion: "That the nursing research project entitled, "Understanding an Acute Episode of Chronic Lung Disease from the Perspective of the Family and Nurse Caregivers" by Pat Bailey, be approved."

When the Ethics Committee report was being presented to the Board at its meeting on September 28th, it was suggested that research projects should go through the proper committees for all of the necessary approvals (medical, ethical, managerial - ie - Research Committee, MAC, Administration, Ethics, Board). Therefore, the Ethics Committee report was presented for information only, and no formal approval was given by the Board.

However, we feel that proceeding with this nursing research project is not a problem, and certainly has the support of Mrs. Susie Perry, here at the hospital. Therefore, you can proceed with your request for this study, as presented to the Ethics Committee by Mrs. Perry.

I trust that this is satisfactory. If you have any questions, please feel free to contact me (office - 673-3655).

Sincerely,

David Innes, Chair
Ethics Committee

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING

INFORMED CONSENT FORM: PATIENT

PROJECT TITLE: Understanding An Acute Episode of Chronic Lung Disease from the
Perspective of the Family and Nurse Caregivers

RESEARCHER: Patricia Hill Bailey

The purpose of this research is to understand the individual, family and nurse(s)' experience of an acute exacerbation of Chronic Obstructive Pulmonary Disease characterised by severe breathlessness, and requiring hospitalisation. Interviews will last approximately one hour. During these interviews questions will be asked about how you and your family manage an acute episode of the illness, how you decide to come to the hospital and what you feel you need from the hospital staff to assist you during this crisis. The nurse will also be asked about her understanding of how families manage an acute episode of Chronic Lung Disease. The interviews will be tape recorded. The tapes will not be shared with the ward staff but publications containing anonymous quotations will be available to everyone at the completion of the study.

There will be no direct benefit for participants from the study, but the information you provide may improve the care for other individuals and families.

THIS IS TO CERTIFY THAT I,

(print name)

HEREBY agree to participate as a volunteer in the above named research project.

I understand that there will be no health risks to me resulting from my participation in the research. I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that the security of the tapes will be maintained at all times. I understand that the information may be published, but that my name will not be associated with the research.

I understand that I am free to not answer any question, and that I may withdraw my consent and terminate my participation in the study at any time, without affecting me (the care of myself or my family) in any way.

I have been given the opportunity to ask whatever questions I desire, and all questions have been answered to my satisfaction.

Participant

Date

Researcher

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING

INFORMED CONSENT FORM: FAMILY CAREGIVER

PROJECT TITLE: Understanding An Acute Episode of Chronic Lung Disease from the Perspective of the Family and Nurse Caregivers

RESEARCHER: Patricia Hill Bailey

The purpose of this research is to understand the individual, family and nurse(s)' experience of an acute exacerbation of Chronic Obstructive Pulmonary Disease characterised by severe breathlessness, and requiring hospitalisation. Interviews will last approximately one hour. During these interviews questions will be asked about how you and your family manage an acute episode of your family member's illness, how decisions are made about coming to the hospital and what you feel you need from the hospital staff to assist you during this crisis. The nurse will also be asked about her understanding of how families manage an acute episode of Chronic Lung Disease. The interviews will be tape recorded. The tapes will not be shared with the ward staff but publications containing anonymous quotations will be available to everyone at the completion of the study.

There will be no direct benefit for participants from the study, but the information you provide may improve the care for other individuals and families.

THIS IS TO CERTIFY THAT I,

(print name)

HEREBY agree to participate as a volunteer in the above named research project.

I understand that there will be no health risks to me resulting from my participation in the research. I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that the security of the tapes will be maintained at all times. I understand that the information may be published, but that my name will not be associated with the research.

I understand that I am free to not answer any question, and that I may withdraw my consent and terminate my participation in the study at any time, without affecting the care of my family in any way.

I have been given the opportunity to ask whatever questions I desire, and all questions have been answered to my satisfaction.

Participant

Date

Researcher

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING

INFORMED CONSENT FORM: NURSE

PROJECT TITLE: Understanding An Acute Episode of Chronic Lung Disease from the Perspective of the Family and Nurse Caregivers

RESEARCHER: Patricia Hill Bailey

The purpose of this research is to understand the individual, family and nurse(s)' experience of an acute exacerbation of Chronic Obstructive Pulmonary Disease characterised by severe breathlessness, and requiring hospitalisation. Interviews will last approximately one hour. During these interviews questions will be asked about your understanding of how families manage an acute episode of Chronic Lung Disease, how they decide to come to the hospital and what they feel they need from the hospital staff to assist them during this crisis. The patient and family will also be asked about how they manage an acute episode of the illness. The interviews will be tape recorded. The tapes will not be shared with other ward staff but publications containing anonymous quotations will be available to everyone at the completion of the study.

There will be no direct benefit for participants from the study, but the information you provide may improve the care for COPD sufferers and their families.

THIS IS TO CERTIFY THAT I,

(print name)

HEREBY agree to participate as a volunteer in the above named research project.

I understand that there will be no risks to me resulting from my participation in the research.

I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that the security of the tapes will be maintained at all times. I understand that the information may be published, but that my name will not be associated with the research.

I understand that I am free to not answer any question, and that I may withdraw my consent and terminate my participation in the study at any time, without affecting me in any way.

I have been given the opportunity to ask whatever questions I desire, and all questions have been answered to my satisfaction.

Participant

Date

Researcher

Physician Letter

Laurentian University

Ramsey Lake Road
Sudbury, Ontario
Canada P3E 2C6

(705) 673-6589
FAX (705) 675-4861
infirmières

Université Laurentienne

Chemin du lac Ramsey
Sudbury (Ontario)
Canada P3E 2C6

(705) 673-6589
Télécopieur: (705) 675-4861



School of Nursing
École des sciences

Understanding an Acute Episode of Chronic Lung Disease from the Perspective of the Family and Nurse Caregiver

Dear Dr

This letter is to inform you that your patient
and their family have agreed to participate in the above research study.

The purpose of this research is to understand the individual, family and nurse(s)' experience of an acute exacerbation of Chronic Obstructive Pulmonary Disease characterised by severe breathlessness, and requiring hospitalisation. Interviews will last approximately one hour. During these interviews questions will be asked about how patients and their families manage an acute episode of the illness, how they decide to come to the hospital and what they feel they need from the hospital staff to assist them during this crisis. The nurse will also be asked about her understanding of how families manage an acute episode of Chronic Lung Disease. The interviews will be tape recorded. The tapes will not be shared with the ward staff but publications containing anonymous quotations will be available to everyone at the completion of the study.

There will be no direct benefit for participants from the study, but the information they provide may improve the care for other individuals and families.

If there are any contraindications to your patient's participation in this research please contact me at the School of Nursing, Laurentian University, Sudbury, Ontario, (705) 673-6589 FAX (705) 675-4861.

Please note that approval for this research study was given by the Sudbury General Hospital Bioethics Committee on October 11, 1995.

Yours sincerely,

Pat Hill Bailey, RN, BN, MHSC, PhD Candidate
Associate Professor

APPENDIX C: PUBLISHED PAPERS

Finding your way around qualitative methods in nursing research⁴¹

Patricia Hill Bailey RN BN MHSC

PhD Candidate, Associate Professor, Laurentian University School of Nursing,
Laurentian University, Sudbury, Ontario, Canada, P3E 2C6

Accepted for publication 16 January 1996

HILL BAILEY P.(1997) *Journal of Advanced Nursing* **25** 18-22
Finding your way around qualitative methods in nursing research The intention of this paper is to assist neophyte and traditionally educated nurse-researchers to navigate the qualitative research literature with understanding. The labelling language describing the central structures of the qualitative paradigm will be discussed as the key element to facilitating insight. The 'trustworthiness' of this research perspective will also be addressed within the context of the nursing research literature.

INTRODUCTION

Finding one's way around qualitative methods in both the social science and nursing literature can present unique challenges to both the neophyte and the quantitatively schooled nurse-researcher. Indeed, decoding the language used by qualitative researchers in order to develop a clear understanding of the historical and philosophical development and the central structures of this newer research paradigm or model can be a formidable task. The intention of this paper, therefore, is to describe the fundamental components of this alternative research strategy and then to clarify the labelling language used in literature on qualitative research methods. Finally, the contentious issue of the 'trustworthiness' of findings based on the interpretive research approach, a recurring theme throughout qualitative writing, will be addressed within the context of the nursing research literature.

THE QUALITATIVE PARADIGM

Any process of formal inquiry is said to be

guided by a set of 'basic beliefs' (Guba 1990). These ideas which form the foundation of a research paradigm or model, are designed to answer three questions: 'what is the nature of knowledge or reality? (ontology), 'what is the relationship between the researcher and knowledge?' (epistemology), and 'how should the inquirer go about finding out knowledge?' (methodology) (Guba 1990 p. 18). The most common research model, quantitative or positivist research

is rooted in a *realist* ontology, that is, the belief that there exists a reality *out there*, driven by immutable natural laws.... Once committed to a realist ontology, the positivist is constrained to practice an *objectivist* epistemology. If there is a real world operating according to natural laws, then the inquirer must behave in ways that put questions to nature and allow nature to answer back directly.... The most appropriate methodology is thus *empirical experimentalism*....
(Guba 1990 p. 19)

Research information in this 'reality-based' paradigm is normally quantified numerically. The newer qualitative research model is based on different ontological and

⁴¹ Copyright 1997 by Blackwell Science Ltd.. Reprinted by permission.

epistemological beliefs. In this paradigm, orientated towards ontology, knowledge or

... realities exist in the form of multiple mental constructions, socially and experimentally based, local and specific, dependent for their form and content on the persons who hold them.

(Guba 1990 p. 17)

Knowledge is relative. The discovery of 'knowledge' (epistemology) is understood as the creation of an interaction between the researcher and researched. The methods of this paradigm (methodology) in the search for 'meaning' involve the analysis of descriptions or discourse.

The increasing use of the qualitative research model as an important strategy for uncovering meaning across a variety of social science disciplines has fostered the development of a number of natural inquiry research methods within the qualitative paradigm itself. These meta-paradigms will be briefly described later in the paper. The novice attempting to locate themselves within this alternative model, however, must initially understand the basic definition of qualitative research and then differentiate between the various epistemological and ontological strategies embodied in its distinct meta-paradigms. Stated most simply, the goal of the qualitative research paradigm is to provide a research methodology for '... understanding the complex world of lived experience from the point of view of those who live it' (Schwandt 1994 p. 118). The researcher's goal within all of qualitative models, regardless of the differing approaches and methods, is to 'interpret' and or 'reconstruct' subjective meanings.

Initially, in the struggle to gain legitimacy in the face of established positivist or experimental principles, the interpretative strategies of determining the meaning of social behaviour, in part, portrayed the belief that social reality did exist in an 'objective' form (Schwandt 1994). That this paradigm initially suggested that knowledge was also 'reality' based. The task of the qualitative researcher, therefore, was merely to describe and interpret the objectively available meanings. Nevertheless, the methods of data collection in the emerging qualitative paradigm were different. Unstructured interviews and participant observation as

opposed to mathematical formulae, were the tools employed to provide access to this reality. Over time, however, changes, perhaps best understood as paradigm extensions, have occurred in the understandings of the origins of social meaning. That is, qualitative knowing has been reconceptualized as being distinct from, rather than an extension of or precursor to, positivist inquiry. Indeed, investigators now believe that the findings of qualitative research are not objective fact but rather subjective interactive constructions which no longer need verification in the quantitative arena.

In addition, qualitative constructionist theory now suggests that reality or meaning is not only subjective in nature, but essentially the construction of participants as they interact within a social environment. Furthermore, interpretation of this reality by qualitative researchers is yet another construction. Such a philosophical shift has precipitate modifications in the focus and attention given to all components of the qualitative research process, including various data collection and analysis strategies (Schwandt 1994, Atkinson & Hammersley 1994). Emancipation from previously rigid methodological protocols now allows for the possibility of the recombination of the quantitative and qualitative paradigms in the search for meaning from more than one perspective (Denzin & Lincoln 1994).

The language of the qualitative paradigm

Given the evolution of the interpretive paradigm, the initial obstacle for the uninitiated lies in unravelling the labelling language used in the qualitative framework (Lowenberg 1993). This unravelling process is a complex task, as several terms are frequently used interchangeably in the literature referring to this research strategy. Analogous to this labelling dilemma is the situation commonly experienced by practitioners when referring to pharmacological agents employed in pain management. Trade names of familiar drugs such as Aspirin, Bufferin and Tylenol are often used in a generic way to denote analgesics in general. However, although it is understood that the labels Aspirin, Bufferin and Tylenol can be used interchangeably in

some situations, the medications are chemically unique and have specific therapeutic indications and contraindications. The professional responsible for the prescription and or administration of these chemical agents must ultimately be familiar with these more specific distinctions.

The same blurring of terminology must be recognized and, where possible, clarified by the neophyte qualitative researcher. To begin demystifying this literature, the reader initially needs to recognize that the qualitative paradigm has evolved from a relatively uncomplicated model which simply focused on the reorientation of knowledge acquisition as description and analysis of human behaviour rather than, like the positivist empirical approach, into a complex paradigm which includes several alternative 'naturalistic' models. Further, it is essential to realize that the development or expansion of this newer research strategy is embodied in the language of qualitative research. In addition, the language of the qualitative paradigm, albeit used inconsistently by researchers, is the clearest reflection of the often confusing evolutionary changes occurring in practical application of research strategies (Thorne 1991, Lowenberg 1993). Although many of the terms are used generically, they are the most accurate signals of the progression of the understandings of the nature of knowledge and knowledge acquisition within the paradigm itself.

As described by Guba & Lincoln (1994), most commonly qualitative research is simultaneously referred to as natural inquiry, interpretive research, hermeneutical research, post-positivism, critical theory, and constructivism. Indeed, these labels are often used in a generic way when discussing qualitative methodologies. The historical and/or linguistic roots for these labels can be identified in the development of this paradigm over the last century, and although these words are used to refer to qualitative research in general, they can also refer to specific research perspectives or meta-paradigms within the qualitative framework (Denzin & Lincoln 1994, Guba & Lincoln 1994).

The term 'natural inquiry' reflects the initial work done by qualitative researchers. It implies the acquisition of knowledge in a manner other than empirical research. Interpretive or hermeneutical research, terms

used interchangeably with natural inquiry, simply refer to the basic nature of qualitative work, that of interpreting meanings within the context of the natural environment. All three terms have a history of use dating back to the inception of the paradigm (Denzin & Lincoln 1994).

Developmental changes

The terms post-positivism, critical theory and constructionalism reflect the gradual ontological and epistemological developmental changes within the paradigm over the last several years (Guba & Lincoln 1994). Post-positivism, for example, which represents the earliest shift from the dominant quantitative experimental paradigm, allows scientists who understand themselves as post-modern researchers, to legitimately mix the quantitative, experimental model, and qualitative, natural inquiry perspectives, in the design of their inquiry. These researchers believe that knowledge exists in the social world and may best be understood using both interpretive and quasi-experimental methods (Guba & Lincoln 1994). Critical theory and constructivism on the other hand, reflect later, more specific reinterpretations of natural inquiry. They focus on such ontological and epistemological concerns as the relationship of the researcher to the informant and the process of constructing meaning itself. Feminist research, a part of critical theory which values the participant as a co-researcher and narrative analysis, a form of constructivism which defines meaning as reconstructions by both the narrator and the researcher, are illustrations of these extensions.

In summary, the language of qualitative research addresses the broad concept of this newer paradigm and the specific ontological and epistemological perspectives of the meta-paradigms.

The word *qualitative* implies an emphasis on processes and meanings that are not rigorously examined, or measured (if measured at all), in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape

inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning.

(Denzin & Lincoln 1994)

PHENOMENOLOGY, GROUNDED THEORY, ETHNOGRAPHY

As the next step in assisting the novice through the qualitative paradigm, a general overview of qualitative methods which cross meta-paradigm structures will be outlined. The following presentation of the three major qualitative methods is intended to illustrate the variation of interpretation in method related to both the ontological and epistemological perspectives within the paradigm. In addition, this description will provide a sense of the frameworks' historical development, thereby outlining the philosophical origins of extensions of these models now emerging. Similar reviews of these main divisions, phenomenology, grounded theory and ethnography have been examined in more depth throughout the social science and nursing literature (Leininger 1985, Parse *et al.* 1985, Munhall & Oiler 1986, Thorne 1991). Although they are presented here as distinct divisions, consensus regarding their definition does not exist across the discipline (Lowenberg 1993). They are, nevertheless, briefly reviewed here in order to begin to demystify this paradigm for the neophyte employing these methods.

Phenomenology Phenomenology, a qualitative approach initially attributed to Edmund Husserl (Thorne 1991), fundamentally attempts to understand '... the nature of being...', the lived experience, through the window of language (p. 182). 'In this framework, the essential task of language is to convey information, to describe reality' (Holstein & Gubrium 1994 p. 263). That is, the researcher using a phenomenological approach to meaning inquiry is attuned to the subjectivity of human understanding and attempts to uncover and describe the essence of 'being' as represented by the informant's language and behaviour in in-depth interviews. In this process, the phenomenologist puts aside or 'brackets' their own perspective. Extensions of the original phenomenological approach have widened

this perspective to include the social interactional nature of experience in the understanding of human meanings and reality. In all forms of this method of inquiry, the researcher presents interpretations of observed lived experience without theory development.

Grounded theory Grounded theory as a form of naturalistic inquiry was first articulated by Glaser & Strauss (1967) in their book *The Study of Grounded Theory: Strategies for Qualitative Research*. This strategy shares the data gathering method of the other qualitative research models. However, for these researchers 'the major difference between this methodology and other approaches in qualitative research is its emphasis upon theory development' (Strauss & Corbin 1994 p. 274). The goal of a theory development method 'grounded' in actual research information was initiated in part by the recognition of a dearth of theoretical understandings in the science of human behaviour. The relationship of this perspective's development to the positivist paradigm is reflected in the model's initial exclusive commitment to inductive theory construction rather than hypothesis testing. Although the model's strength continues to be its systematic methodological strategies, '... constant making of comparisons... systematic asking of generative and concept-relating questions, theoretical sampling, systematic coding procedures...' (Strauss & Corbin 1994 pp. 274-275).

Strauss & Corbin's recent extensions recognize '... the potential role of extant (grounded) theories and the unquestionable fact (and advantage) that trained researchers are theoretically sensitised' (Strauss & Corbin 1994 p. 277). Using grounded theory as a form of qualitative inquiry, the development, or reconfirmation, of theoretical constructs continues to be the fundamental task of the researcher.

Ethnography Ethnographic research has a long history. At the beginning of this century, ethnography was used in cultural anthropology to study and describe alien societies (Hammersley 1990). For qualitative researchers '... the central aim of ethnography is to understand another way of life from the

native point of view' (Spradley 1979 p. 3), an emic perspective. According to Spradley (1979), this method is concerned with developing in-depth descriptions of '... meanings of actions and events to people' (p. 5) through the primary processes of participant observation and in-depth interviewing of 'key' or knowledgeable informants. Similar to phenomenology, specific methodological strategies have been developed to analyse data.

Ethnography is a way of collecting, describing, and analysing the ways in which human beings categorise the meaning of their world. In other words, ethnography attempts to learn what knowledge people use to interpret experience and mould their behaviour within the context of their culturally constituted environment.

(Aamodt 1991 p. 41).

There has been an increasing adoption of ethnographic methods by many social scientists, including those in education, health care, human geography, organization studies, and social policy (Atkinson & Hammersley 1994). The attempt to understand social realities in these applied disciplines using an ethnographic approach has coincided with complex adaptations in the traditional strategies. Depending on the research questions and cultures being examined within these disciplines, the 'field' or scope of data collection, the attention to 'spoken interaction' or recorded text and the 'voice' of the informant or presentation of findings privileging the 'teller' rather than researcher has led to complex changes or extensions in this method. Narrative analysis, a form of research which focuses on the structure, content and context of ethnographic interview data, is an example of extension in the ethnographic paradigm. The responsibility of interpreting meanings in all forms of ethnographic research, nevertheless, remain the purview of the researcher.

In summary, broadly defined,

qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied

use and collection of a variety of empirical materials... that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand.

(Denzin & Lincoln 1994 p. 2)

QUALITY IN QUALITATIVE RESEARCH

Finally, the most controversial issue that has faced the adoption of qualitative research methods generally, and specifically within the field of nursing research, has been concern surrounding the value or 'trustworthiness' of interpretive research findings (Lowenberg 1993, Sandelowski 1993). A clear understanding of this essential issue is difficult to untangle from the discussions presented in the literature. As indicated, until recently positivism was the dominant research strategy used by quantitatively educated nurse-researchers. The nursing literature therefore reflects the attempts of these scientists to either minimize the importance of this question within the qualitative framework or reinterpret the validity and reliability criteria essentially unchanged from the more familiar positivist paradigm (Field & Morse 1985, Sandelowski 1993).

As discussed, the goal of interpretive inquiry is to understand meaning not 'truth'. Hence, some qualitative scientists now recognize that the transfer of credibility criteria, validity and reliability, from the positivist to the interpretive paradigm is not automatic or even reasonable. These researchers have reconceptualized the issue of quality. For them the value of authenticity of qualitative research findings is determined through a process of 'validation' (Polkinghorne 1988, Mishler 1990, Thorne 1991, Sandelowski 1993, Riessman 1993). That is, the authenticity of qualitative research is determined not by mathematical formulae, but rather by adjudication by both the consumers and fellow researchers. The essential premise of this process is that the qualitative scientist in the presentation of their work make the research process adequately visible and hence auditable. Although the literature describing this evolving understanding of the 'process of validation' on occasion continues to blur the quality issues

between paradigms, a recognition of this process by the neophyte is also essential in order to decipher the confusing qualitative literature.

CONCLUSION

Acquisition of an understanding of the complex nature of qualitative research as presented in the literature by the neophyte or quantitatively schooled nurse-researcher, can be extremely daunting. A clear grasp of the basic purpose of interpretive inquiry is initially important in beginning to understand the breadth of this newer research paradigm. In approaching this body of literature, one must also recognize that the historical evolution of this research perspective has resulted in the development of meta-paradigms.

Further, it becomes apparent that these meta-paradigms embody the variation in ontological and epistemological perspectives, basic methodological divisions, and the alternate approach to quality, validation, now recognized under the larger qualitative umbrella. This paper has demonstrated that although definitions of these various perspectives and method divisions are either unclear or blurred, comprehension of the evolving qualitative structure and language can facilitate the decoding of this literature.

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Assuring Quality in Narrative Analysis^{* 42}

Patricia Hill Bailey

Many nurse-researchers using qualitative strategies have been concerned with assuring quality in their work. The early literature reveals that the concepts of validity and reliability, as understood from the positivist perspective, are somehow inappropriate and inadequate when applied to interpretive research. More recent literature suggests that because the positivist and interpretive paradigms are epistemologically divergent, the transfer of quality criteria from one perspective to the other is not automatic or even reasonable. The purpose of this article, therefore, is to clarify what the terms quality, trustworthiness, credibility, authenticity, and goodness mean in qualitative research findings. The process of assuring quality, validation, in qualitative research will be discussed within the context of the interpretive method, narrative analysis. A brief review of quality in narrative analysis nursing research will also be presented.

The formal recognition in nursing of the qualitative paradigm as an acceptable research perspective has occurred within the last decade (Field & Morse, 1985; Leininger, 1985; Morse, 1991; Munhall & Oiler, 1986). Nurses have only recently assumed a research role, and nurse-researchers, mainly schooled in the positivist tradition, have, until the last few years, been hesitant to embrace qualitative methods. The traditional perception of the questionable validity and quality of this alternative research framework by the larger scientific, essentially positivistic community may, in part, account for this reluctance (Hunt, 1991).

The more recent increase in the use of the interpretive or constructionist research strategies by nurses-researchers coincides with the general increasing acceptance of the qualitative paradigm as a viable model for social science research (Oiler Boyd, 1993). Nurses-scientists also now recognize

the philosophical fit of the qualitative paradigm with the values and beliefs that have long characterized nursing practice.....The hearty emergence of qualitative research in nursing can be attributed to the desire to develop knowledge in the discipline in accord with the practice that such knowledge serves. (Oiler Boyd, 1993, p.9)

The main traditions of qualitative research-phenomenology (Anderson, 1990), grounded theory (Chenitz & Swanson, 1986), and ethnology (Aamodt, 1989)-have all been used to guide nursing investigations (Lowenburg, 1993). Although these traditions have developed more or less defined strategies for data interpretation, nurse-researchers nevertheless continue to express great concern regarding the preservation of methodological rigor within this alternative paradigm (Morse, 1991; Sandelowski, 1993; Thorne, 1991). For some researchers, the concern over validity and reliability has translated into methodological inflexibility. Still others appear to ignore the issue of validity, as evidenced by the lack of reference to these issues in the accounts of their work (Morse, 1991; Sandelowski, 1993).

Relatively new extensions of these paradigms-such as narrative analysis, the systematic study of stories commonly found in ethnographic interviews are in the developmental stages. For the interpretive researcher using narrative analysis, "the historical truth of an individual's account is not the primary issue" (Riessman, 1993, p. 64). It is understood that participants reconstruct reality in giving meaning to their lives. As Williams (1984) wrote, these "narrative reconstructions [are] attempts to account for and repair breaks in the social order" (p. 193). They are meaning-making events interpreted by the teller, then the analyst. It is the reconstruction of meaning, not truth, that the researcher wishes to understand and then

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reinterpret theoretically. Ensuring quality in narrative analysis research as a component of the qualitative tradition has been problematic (Riessman, 1993).

Although the adoption of this emerging qualitative method by nurse researchers allows for unique extensions of the ethnographic framework within the context of nursing research (Sandelowski, 1991; Tilley, 1995; Vezeau, 1994), the lack of widely accepted established protocols further exaggerates the already contentious quality dilemma (Smith, 1990). It is, therefore, essential that nurse-researchers clarify how the quality of these inquiries can be ensured. The purpose of this article, therefore, is to clarify what is meant by the concept of quality in qualitative research findings. The process of assuring quality, *validation*, in qualitative research will be discussed within the context of the interpretive method, narrative analysis.

TRADITIONAL MEASURES OF QUALITY

The literature refers to the concept of quality in qualitative research in a variety of ways. The alternative terms used by interpretive researchers include *trustworthiness*, *credibility*, *authenticity*, and *goodness*. Traditionally, the quality of any research finding was determined by critiquing the validity and reliability of the research process. 'That is,

until recently ... valid research was distinguished from invalid research in terms of the extent to which the proper procedures were properly applied.... For empiricism a judgement about the quality of research was in effect a judgement about methodology; valid studies were procedurally correct, inept studies were procedurally flawed. (Smith, 1990, pp. 168-169)

For researchers engaged in qualitative work in which methods are variable and flexible and the researcher is the essential research tool, the application of these concepts has historically been regarded as enigmatic (Brink, 1987, 1991). In the early 1980's, interpretive researchers nevertheless continued to search for and defend against what they labelled *sources of error* as articulated by the positivist model. Indeed, "a common criticism directed at putative qualitative investigation [was] that it fails to adhere to cannons of validity and reliability" (LeCompte & Goetz, 1982, p. 31). This early literature, however, revealed the uneasy realization that the concepts of validity (objective truth) and reliability (the stability of findings over time), as understood from the positivist perspective, were somehow inappropriate and inadequate when applied to interpretive research (Lincoln & Guba, 1985; Mishler, 1990).

Several scholars have addressed these concerns in an effort to resolve or at least clarify the quality dilemma (Agar, 1986; Brink, 1987; Guba & Lincoln, 1989; Hammersley, 1990, 1992; Kirk & Miller, 1986; Lincoln, 1990; Lincoln & Guba, 1985; Marshall, 1990; Mishler, 1986; Polkinghorne, 1988; Riessman, 1993; Sandelowski, 1993; Smith, 1990). An initial clarifying strategy for some qualitative scientists has been to make the interpretive process more explicit. For example, in an attempt to enhance possible communication between positivist and interpretive scientists, Agar (1986), an ethnographer, outlined a language structure for ethnography that relabels the ethnographic process of data analysis in a more explicit and systematic manner. *Strips* are defined as the basic data units, and the development of *schema* denotes the evolving frame used to determine *meaning*. *Resolution* describes the process of understanding *breakdowns* or differences in experience from the ethnographer's culture and that of the tradition under study. The ultimate objective of ethnographic work is *coherence-a* reinterpretation of the differences in the language of the researcher's world from that of the study population's culture. Agar's goal was to illustrate the methodological rigor of ethnography in understandable and consistent terms and hence to address indirectly the issue of validity and reliability and quality within this paradigm. Although his approach assists in illustrating the increasingly systematic nature of qualitative data analysis, it neither directly addresses the philosophical differences in the paradigms nor resolves the credibility debate.

Lincoln and Guba (1985), who are educational researchers, further illustrate the unsatisfactory philosophical entanglement of the two paradigms in their original consideration

of this issue of quality. These researchers substituted what they proposed were equivalent terms for quality from the positivist to the interpretive paradigm. They relabelled these concepts as trustworthiness criteria. Their trustworthiness criteria initially acknowledged the established positivist *rigor* criteria as superior and were, therefore, an attempt at ensuring some scientific acceptability of qualitative findings. In their model *internal validity* was replaced with *credibility*, *external validity* with *transferability*, *reliability* with *dependability*, and *objectivity* with *confirmability* (p. 300).

In answer to the question "how can we assess the validity of a narrative interpretation?" (Mishler, 1986, p. 108), the early writing of narrativists (Mishler, 1986; Polkinghorne, 1988), defending interpretive methodology, again demonstrate that most qualitative researchers initially approached the issue from a very positivist perspective. Polkinghorne (1988), a clinical psychologist engaged in narrative analysis, began his discussion of the evaluation of quality in narrative inquiry by using three of the concepts central to the quantitative/positivist paradigm: validity, reliability, and significance. He suggested that the quality of interpretive research using stories can be determined when the same terms used by the received tradition are merely understood as broader concepts.

For Polkinghorne (1988), quality in narrative findings can be evaluated by simply employing alternate, more common-use meanings for these ideas. He argued, therefore, that validity in narrative analysis should be understood as *verisimilitude*- "results that have the appearance of truth or reality" and that are "well grounded and supportable" (p. 176). In addition, reliability refers not to the reproducibility of a similar story on a subsequent occasion but, rather, to the dependability of the one-time narrative database. Finally, he suggested that significance should be measured by determining whether the results of narrative analysis are meaningful or important rather than referring to the strength of statistical calculations. This redefinition of terms conventionally used in quantitative research, however, does not explicitly address the epistemological differences inherent in the qualitative paradigm. The search for meaning rather than truth is not discussed, and the discussion, therefore, further illustrates the inadequate coalescing of the two paradigms.

NEW WAYS OF DEFINING QUALITY IN QUALITATIVE RESEARCH

In recent years, an extensive dialogue concerning the value or quality of qualitative research has occurred (Guba, 1990). As a result, alternative ways of determining the quality of knowledge generated within the interpretive paradigm have emerged. These strategies are based on a recognition of paradigmatic epistemological differences. The language of this dialogue reflects the evolution in the understanding of this concern. In this literature, research findings are now evaluated for trustworthiness, credibility, authenticity, and/or goodness. This work reflects a fresh understanding with respect to both validity and reliability within the community of qualitative researchers.

It is now recognized that the notion of validity when employed within the interpretive paradigm must not just be redefined but reconceptualized. Lincoln (1990) has now stated that the trustworthiness criteria that he and Guba (1985) originally developed "had their foundation in concerns indigenous to the conventional, or positivist, paradigm" (Lincoln, 1990, p. 71) and were, therefore, inappropriate. Lincoln, therefore, reconceptualized the trustworthiness criteria, which were based on the ontology of positivism (truth), as authenticity criteria based on the relativism of the qualitative model. Ale authenticity criteria, in part, now reflect "the need for such inquiries to express multiple, socially constructed, and often conflicting realities" (Lincoln, 1990, p. 72). Explicit authenticity criteria, however, are still not identified. Ale term *goodness* has also been used by qualitative researchers in debating the nature of and/or need for criteria to be used to differentiate between valid and invalid qualitative research (Heshusius, 1990). Although the qualitative paradigm has matured, the issue of quality assurance and evaluation in the paradigm as a whole continues to be unresolved.

QUALITY IN NARRATIVE ANALYSIS

The recent writings of researchers engaged in narrative analysis reflect the evolving understanding and complexity of the quality issue within the interpretive perspective (Mishler, 1990; Riessman, 1993). Narrativists refer to the reconceptualization of validity and reliability within the interpretive/constructionist paradigm as a process. For these researchers, this reformulation using terms such as *trustworthiness* and *credibility* has positively changed validity from an objective reality to the process of confirmation/validation:

Validation, the process through which we make claims for the trustworthiness of our interpretations, is the critical issue. Trustworthiness not truth is a key semantic difference: the latter assumes an objective reality, whereas the former moves the process into the social world. (Riessman, 1993, p. 65)

Through the process of validation, the researcher allows the readers, fellow researchers, to judge the authenticity and trustworthiness of her or his work. This process is not merely the employment of two or more raters during the analysis of data to ensure equivalence (Brink, 1987) or *member checks* to affirm the researchers' interpretation (Riessman, 1993). Rather, to date, the predominant strategy in narrative analysis of the confirmation or validation activity is simply to make the research process visible, allowing systematic scrutiny (Mishler, 1990; Polkinghorne, 1988; Riessman, 1993; Sandelowski, 1993).

For narrativists, credible and valuable narrative interpretation presents

data in the form of the texts used in the analysis, with full transcripts and tapes that can be made available to other researchers; ... methods that transformed the texts into findings; and ... the direct linkages shown between data, findings, and interpretation. (Mishler, 1990, p. 429).

The presentation of data in this manner enhances the authenticity of the findings by not privileging the researcher as the sole interpreter. Indeed, there is not just one correct interpretation of the structures, meanings, or context of narratives. Moreover, there is no specific set of rules that if followed confer credibility. Rather,

trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable: it is less a matter of claiming to be right than to have practiced good science. (Sandelowski, 1993, p. 2)

QUALITY IN NARRATIVE ANALYSIS NURSING RESEARCH

To date, the use of narrative analysis in nursing research has been limited. A review of this work in another article (Bailey, 1995) outlines the preliminary endeavours of nurse-researchers in the use of narrative as a window to the understanding of nursing care situations. Work reporting narrative nursing research illustrates the continuing challenge facing researchers of adequately addressing the issue of quality in the presentation of qualitative findings (Benner, Tanner, & Chesla, 1992; Cooper, 1991; Heikkinen, 1993; Sandelowski, Holditch-Davis, & Harris, 1990; Schroeder & Maeve, 1992; Tanner, Benner, Chesla, & Gordon, 1993; Udén, Norberg, Lindseth, & Marhaug, 1992). Three common concerns were identified in the representative studies reviewed. These included unclear descriptions of the methods used, inadequate presentations of results, and/or little or no information addressing the validation strategies employed.

For example, the presentation of methodological strategies frequently demonstrated a blurring of the analysis models of grounded theory (constant comparisons) and narrative analysis (contextual analysis of stories). Indeed, it was generally difficult to discern the precise use of narrative theory. Further, the authors' presentation of the research findings were inconsistent with the narrative genre. The authors either identified themes with or without colleague collaboration or interpreted the stories for the readers, presenting selective quotes

supporting the theme selection. Their presentations, however, privilege the researchers' interpretation (Riessman, 1993, p. 32). Basic strategies for validation of the analytic process that are normally present in narrative analysis, including the presentation of original data, transcription information, and a clear outline of each step of the reconstruction process, were consistently missing (Mishler, 1990; Ochs, 1979; Riessman, 1993; Sandelowski, 1993). Hence the opportunity for the reader to validate the interpretations or draw alternate conclusions was forfeited.

In summary, qualitative scientists are now able to articulate that because the positivist and interpretive paradigms are epistemologically divergent, the transfer of quality/credibility criteria from one perspective to the other is not automatic or even reasonable. That is, the experimental model presupposes an objective and measurable reality or truth, whereas the interpretive approach is interested not in truth but in meaning (Chinn, 1994). The evaluation of quality in qualitative research and, more specifically, in narrative analysis must now be understood using a reconceptualization of the concept of validity as the process of validation. The validation concerns identified in the narrative nursing research literature include the need to clearly outline the research methodology and to present the findings so that fellow researchers and consumers may participate in the evaluation of the researcher's analysis. Finally, to ensure the importance of narrative work, strategies must be developed to overcome the obstacles of adequately incorporating these requirements into professional journal reports (Polit & Hungler, 1989).

NOTE

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